Author:
Clark, Sian

Title:
Life-Stories of Young People Labelled with Autistic Spectrum

Life-Stories of Young People Labelled with Autistic Spectrum

by

Sian Clark

A dissertation submitted to the University of Bristol in accordance with the requirements for award of the degree of Doctorate in Educational Psychology in the Faculty of Law and Social Sciences

Norah Fry Research Centre, School of Community and Health Studies

December 2009

Word count: 48, 295

ABSTRACT

This study explored the life experiences of young people labelled with autistic spectrum, through collaboratively creating their life-stories with them. Implications for educational psychology practice were subsequently considered.

Although there is an abundance of autistic spectrum research within medical and developmental psychology fields, the voice of young people themselves, who are labelled with autistic spectrum, is often marginalized or absent. The current study sought to remedy this gap. Life-stories were undertaken with five young people attending a specialist autistic spectrum provision within a large rural county. The stories were analysed using a thematic narrative analysis technique and the themes to emerge from the stories were explored. These included a strong focus on the social barriers experienced by participants, although autistic spectrum impairments were also evident. Implications of the findings were noted with regard to professional educational psychology practice.

ACKNOWLEDGEMENTS

I am very grateful to the young people who took part in the study, their parents and the manager of the specialist autistic spectrum school attended by participants.

I would like to particularly acknowledge the insightful guidance of my supervisor Professor Kelley Johnson.

I would also like to thank Dr. John Franey, Maggi Walton, the Norah Fry Centre staff and the Education Library staff. Special thanks to my husband for all his help and support.

DECLARATION

I declare that the work in this dissertation was carried out in accordance with the requirements of the University's Regulations and Code of Practice for Research Degree Programmes and that it has not been submitted for any other academic award. Except where indicated by specific reference to the text, the work is the candidate's own work. Work done in collaboration with, or with the assistance of others, is indicated as such. Any views expressed in the dissertation are those of the author.

Signed Siân Clun Date 26.3.10

CONTENTS

LIST OF PHOTOGRAPHS

CHAPTER ONE: INTRODUCTION

There is a lack of exploration of the life experiences of young people labelled with autism in the research field to date. The current study sought to improve understanding of how a small group of these young people saw their own lives, through collaboratively creating stories about their life with them.

Rationale

Autism was first highlighted as a medical condition by Kanner (1943) and its variant "Asperger's Syndrome" defined by Hans Asperger the year after. Kanner considered that autism prevented children from forming the usual biologically-based emotional attachments to others, and that they displayed a "powerful desire for aloneness" (Kanner 1943:249). Since Kanner's early work, historical perspectives on the medical label autism have evolved. In the 1950s for instance, viewpoints around its causative factors moved away from a focus on biology towards more psychological considerations, with a particular focus on the traumatic influence of the "dysfunctional family" supposedly resulting in autism (Smith 1996). From the late 1960s this led to the suggestion that cold and distant mothers might cause children to be autistic (Hobson 1993a; cited in Trevarthen 1996). However since the 1970s, a biological focus on autism has returned within the medical field. Whilst some confusion remains over exact diagnostic terms (Kabot, Masi and Segal 2003), autism is currently considered to be a biological neurodevelopmental disorder (Bailey, Phillips and Rutter 1996; Rutter 2005) with an accompanying genetic component (Lauritsen, Mors, Mortensen and Ewald 1999).

The autism research field is dominated by a medical model, with its prevailing discourse of epidemiology, assessment and diagnosis. Another perspective is offered by developmental psychology, the aim of which is to more fully understand autism from a social, emotional, language and cognitive point of view. However even here there are many overlaps with a medical perspective: For instance both the medical and developmental psychology literature share a focus on the discourse of deficit and disorder (Lobianco and Sheppard-Jones 2007). An alternative social model

perspective (Oliver 1990) on the other hand is not concerned with individual deficit, rather aims to identify the social barriers that stop people from living full lives.

A medical model of autism is based on a realist ontology and positivist epistemology, where reality is viewed as fixed, objective and measurable and exists separately from human beings (Cohen, Manion and Morrison 2000; Robson 2002; Bryman 2004). Medical and developmental psychology research into autism tend to use positivist research paradigms. A social constructivist epistemological stance is much less common. Here, reality is not considered as fixed and objective, rather it is subjective and evolving according to each individual. Moreover "subjective meanings are negotiated socially and historically" through language (Creswell 2007:21). As such there is not one truth, rather there are multiple truths (Manthei 1997). According to this view, a medical label such as autism does not represent a fixed objective reality, rather the label is a construct that develops through human social communication and interaction (Gillman, Heyman and Swain 2000).

It is noteworthy that childhood autism diagnoses are usually arrived at through discussions between doctors and parents (and sometimes teachers). The views of the children and young people themselves are not often sought. Assuming that the very foundations of the medical label autism are to be questioned, a route towards this may be to better understand the life experiences and perspectives of the young people themselves who are labelled. This type of exploration is currently missing within the autism research field.

I developed a personal interest in the medical condition of autism ten years ago during my early studies as a psychologist. Whilst learning about autism at the time, I was fascinated by its potential to help me understand child psychology - both "normal" and "abnormal" (as I viewed it then). Since then and during further training as an Educational Psychologist (EP), my own perspectives on autism have evolved. Whilst retaining a strong interest in the psychological foundations of children and young people who have been given the autism label, my focus has shifted away from the child-deficit view permeating medical and traditional developmental psychology (Wagner and Gillies 2001; Frederickson and Cline 2002). Instead, I have been introduced to a social model of disability (Oliver 1990).

According to this model, challenges experienced by children with autism are not caused by individual impairment, rather by the processes of social exclusion that result from these impairments.

As a Trainee Educational Psychologist (TEP) I have developed an interest in those assessments and interventions, which are linked to a social constructivist perspective. For instance I have been drawn to techniques specifically designed to support children in giving their views a voice, as well as to approaches geared at maximising environmental interventions, rather than focussing narrowly on children's individual difficulties. Such fields of interest also have links with a "Positive psychology" orientation. As highlighted by Seligman and Csikszentmihalyi (2000),

> ...Our message is to remind our field that psychology is not just the study of pathology, weakness and damage; it is also the study of strength and virtue. Treatment is not just fixing what is broken; it is nurturing what is best. Psychology is not just a branch of medicine concerned with illness or health; it is much larger. It is about work, education, insight, love, growth and play...Positive psychology....tries to adapt what is best in the scientific method to the unique problems that human behaviour presents to those who wish to understand it in all its complexity.
>
> (Seligman and Csikszentmihalyi 2000, p.7)

As my EP training progressed, I continued to maintain an interest in developmental psychology perspectives on autism, whilst simultaneously questioning some of the processes involved in its medical and psychological assessment and diagnosis. I was particularly concerned at the lack of research undertaken into the lived experience and perspectives of the very children and young people who are labelled. I was aware that many autobiographies had been published by adults with the autism label (e.g. Williams 1992; Lawson 1998; Holliday Willey 1999; Tammet 2006), and also published by parents of – and sometimes with - their autistic children (e.g. Barron and Barron 1992; Stevens and Stevens 2008). By reading a small selection of these (Barron and Barron 1992; Williams 1992; Holliday Willey 1999; Tammet 2006; Stevens and Stevens 2008), I hoped to improve my understanding of the life experiences of children and young people labelled with autism, albeit indirectly through the retrospective eyes of diagnosed adults and their families.

A central research question developed from these and other readings, namely:

How do young people with the autistic spectrum label see their lives and experiences?

As this primary research question was concerned with understanding lived experience (rather than measuring an external notion of a fixed reality), a qualitative methodology was deemed appropriate. Moreover, having read several published autobiographies written by adults with the autism label, I became increasingly interested in the potential for eliciting information about the life experiences of younger people with the diagnosis. As such consideration was given to the potential for creating life-stories with individual young people labelled with autism.

A second related research question developed from the primary question, namely

How do these life experiences relate to theoretical models and disciplinary perspectives?

Early readings of published autobiographies were undertaken with the broad aim of better understanding the life experiences of children and young people with an autism diagnosis. Initially, this was to aid preparation for subsequent work with teenagers labelled with autism, which was to constitute the main study. However in the event possibilities for this were limited, as will be revealed in due course. Instead, as the study progressed, two published autobiographies became a specific vehicle for experimenting with a data analysis approach, in order that lessons could be learnt with regard to data analysis within the main study.

Thesis Structure

With reference to these research questions, ***Chapter Two: Literature Review*** will include an analysis of a range of theoretical models for considering autism, whilst relevant research will be critically explored. This will be followed by a review of the literature relevant to a young person's view on autism.

Chapter Three: Methodology will contain a description of the methodology of the present study, as well as an outline of the data collection and analysis techniques employed. In ***Chapters Four – Eight***, five life-stories created collaboratively with young people labelled with autism will be presented, and themes to emerge from the stories are considered in ***Chapter Nine: Discussion of Themes***. Finally ***Chapter Ten: Conclusions and Implications for Practice*** will review implications of the current findings for professional educational psychology practice.

Definition of Terms

The current study was located within the *narrative inquiry* research tradition. This field incorporates a variety of research methods, all sharing "an interest in biographical particulars as narrated by one who lives them" (Chase 2005:651). The term *narrative* can be used to denote a dominant social discourse when referring to "metanarratives" or "grand narratives" such as science and religion (e.g. Clandinin and Connelly 2000). However Chase (2005) defines a *narrative* primarily as the following:

> a) A short topical story about a particular event and specific characters such as an encounter with a friend, boss or doctor; b) an extended story about a significant aspect of one's life such as schooling, work, marriage, divorce, childbirth, an illness, a trauma, or participation in a war or social movement; or c) a narrative of one's entire life, from birth to the present.
>
> (Chase 2005)

The current study involved using a research method for eliciting narratives (adopting Chase's definition of narrative), known as the *life-story method* (e.g. Goodley 1996; Atkinson 1998; Atkinson 2004). This involved co-constructing specific kinds of narratives known as *life-stories* with individual participants. As life-stories are particular forms of narrative, their definition often overlaps with some of the definitions of narrative above (Chase 2005): For instance, they are sometimes ""birth-to-present narratives" (Atkinson 2002; cited in Chase 2005); at other times they relate to more specific aspects of a person's life, as in definition (b) above (Chase 2005). The life-stories in the present study were treated as data and analysed using *narrative analysis*: Narrative analysis is defined in the current study as a range of tools for analysing narrative data. The implications of the current study related to

professional educational psychology. As such it was appropriate particularly during the data analysis phase, to consult the discipline of psychology within the narrative inquiry field, known as *narrative psychology*. The specific tool for the narrative analysis of the life-stories was therefore selected from the narrative psychology field.

CHAPTER TWO: LITERATURE REVIEW

Since Kanner's original identification of the medical condition autism, its nature has been significantly contested through the decades, both within medical circles and beyond. Bearing in mind the research questions highlighted above, there are three parts to this literature review. ***Part One*** will describe both a medical and developmental psychology perspective on autism. The implications of these perspectives will be explored in relation to their respective potential to offer an insight into the lived experience of young people with the autism label.

In ***Part Two*** alternative social perspectives on autism will be similarly explored, followed in ***Part Three*** by a review of the literature relevant to the perspective of young people with the autism label. The latter will be undertaken with a specific view to the methodological framework of the current study.

Part One: Medical and Psychological Perspectives

A Medical Model and the Autistic Spectrum

Diagnosis

It was not until the 1980s that a degree of consensus was reached around the prevailing features that constituted a medical diagnosis for autism (Rutter 2005). Until then a plethora of terms were used such as "Infantile Psychosis", "Infantile Autism" and "Autistic-like conditions", with no apparent consistency in their relative usage. It is now considered that the medical definition of "Autistic Disorder" as described in the DSM-IV (American Psychiatric Association 1994; summarised in Kabot et al. 2003) is the most widely accepted:

> According to the DSM-IV, autistic disorder is one of several pervasive developmental disorders (PDDs) that are caused by a dysfunction of the central nervous system leading to disordered development. All children with PDD are characterized by qualitative impairments in social interaction, imaginative activity and both verbal and non-verbal communication skills. Additionally they have a limited number of interests and activities, which tend to be repetitive, and the manifestation of symptoms occurs within the first three years of life.
>
> (Kabot et al. 2003, p.26)

There are five pervasive developmental disorders including "Autistic Disorder", "Asperger's Syndrome" and "Pervasive Developmental Disorder – Not Otherwise Specified" ("PDD-NOS") (Kabot et al. 2003). "Autism" or "Autistic Disorder" is differentiated from "Asperger's" within the medical field, as the significant language and cognitive delay usually seen in "Autistic Disorder" is considered absent in "Asperger's" (Trevarthen 1996). In practice within the research literature, "Autistic Disorder" and "Asperger's" are often viewed as different manifestations of the same condition albeit manifesting differing degrees of severity. As such, they are regularly considered to be located along a "spectrum", hence the term "Autistic Spectrum Disorder" (Gillberg 1992).

There is a danger that medical diagnoses that use a realist ontological interpretation of diagnostic categories are viewed by medical professionals as absolute certainties that are fixed and static (Gillman 2004). It could be argued that both medical and some psychological practices of assessment and diagnosis have the effect of oppressing a disabled minority (Swain, French and Cameron 2003), and can be a way for doctors and psychologists to gain professional territory (Gillman 2004). Moreover and ironically behind this exterior of professional certainty, there remains much confusion in medical circles around the difference between "Autistic Disorder" and "Asperger's", as well as around differential diagnoses for "PDD-NOS", "Autistic Disorder" and "Asperger's" (Gillberg 1998; Kabot et al. 2003). In addition, the label "Asperger's" is sometimes used interchangeably with "High-Functioning Autism", (Lasser and Corley 2008) and a consensus has not yet been reached around whether there is a difference between the criteria for either diagnosis (Volkmar and Klin 2005; cited in Reilly, Campbell and Keran 2009).

As such and for the purposes of the present study, the term ***autistic spectrum*** (Gillberg 1992; Trevarthen 1996) will be adopted to encompass both "Autism" / "Autistic Disorder" as well as "Asperger's Syndrome" and / or "High-Functioning Autism". However, on reviewing specific research studies, the medical labels used in the individual studies will be adopted and placed within quotation marks to indicate this.

Epidemiological research

There is a wealth of epidemiological research undertaken from a positivist epistemological stance into the autistic spectrum. For instance, Steffenburg and Gillberg (1986) carried out a prevalence study using medical professionals to confer "Infantile Autism" and "Autistic-like condition" diagnoses on children who were their patients. The diagnoses were defined using the criteria of the DSM-III (American Psychiatric Association 1980; cited in Steffenburg and Gillberg 1986). Out of a total sample of 78, 413 children born between 1975 and 1984 in Sweden, a total rate of 6.6 per 10,000 of children were diagnosed, two thirds of whom with "Infantile Autism" and the rest with "Autistic-like conditions". Girls were five times less likely than boys to be diagnosed. A similar study was carried out by Ehlers and

Gillberg (1993), however this time the focus was on "Asperger's Syndrome". Here, it was teaching rather than medical professionals who took the lead in diagnosing children and the criteria used for "Asperger's" as outlined by Gillberg and Gillberg (1989) and updated by Gillberg (1991; cited in Ehlers and Gillberg 1993). Again in Sweden, out of a total number of 1,519 children between 7 and 16 years old, it was found that 3.6 per 1000 children fitted the diagnostic criteria for "Asperger's", with four times as many boys than girls being diagnosed.

More recently Baird, Charman, Baron-Cohen, Cox, Swettenham, Wheelwright and Drew (2000) undertook a UK-based epidemiological study of 16,235 children aged 18 months, who were followed up at age 3, 5 and 7 years of age. The sample was taken from ten health districts in the South East Thames Health Region, UK. Parents and teachers were used to gather information, which medical professionals used to make diagnoses of "Autistic Spectrum Disorder" using the ICD-10 criteria (World Health Organization 1993; cited in Baird et al. 2000). This time a provisional rate of 30.8 per 10,000 was found, with fifteen times as many boys than girls diagnosed. This represented a higher prevalence rate and a higher male: female ratio than in previous studies, although the authors considered that the overlap in the sample between "Autistic Disorder," and "Asperger's" partly accounted for this increase. In another UK-based study, Chakrabarti and Fombonne (2005) found a rate of 22 per 10,000 of children who met the medical criteria for "Autistic Disorder" using the DSM-IV criteria (American Psychiatric Association 1994; cited in Chakrabarti and Fombonne 2005). Lastly and also a UK study, Baron-Cohen, Scott, Allison, Williams, Bolton, Matthews and Brayne (2009) found a prevalence rate of 157 per 10,000 of "Autism-spectrum conditions" (Baron-Cohen et al. 2009:500)

There are difficulties in epidemiological research comparisons owing to changing diagnostic categories and terminology over time, methodological differences between studies (Baird et al. 2000) as well as wider cultural differences. However it is clear that the incidence of children who meet the criteria for a medical autistic spectrum diagnosis are rising, although the reasons for this are currently undefined (Rutter 2005). It is also apparent that boys are more likely than girls to be diagnosed, particularly where there is no associated learning disability or cognitive delay (Wing 1981; Steffenburg and Gillberg 1986).

From studies such as these, we know the broad picture of distribution of the autistic spectrum, when it is considered as a diagnosed condition from the perspective of a medical model. We also know that usually up to seven times as many boys than girls are diagnosed (Rutter, Caspi and Moffitt 2003). However quantitative research such as this does not seek to question the medical diagnoses themselves, nor does it interrogate the processes involved in reaching these diagnoses. The perspectives and life experiences of the young people who are at the centre of such processes usually remain unexplored when diagnoses are made.

A Developmental Psychology Perspective on the Autistic Spectrum

A psychological perspective is concerned with uncovering the reasons behind human behaviour (Carlson and Buskist 1997). Psychology perspectives have tended therefore to focus on the behaviours associated with the autistic spectrum rather than on its epidemiology, although developmental psychology often informs a medical perspective (Jordan and Powell 1995). As such it could be argued that there are strong links between a medical model and a developmental psychology view of the autistic spectrum. Both use positivist interpretations of the autistic spectrum label, and both share a discourse of abnormality, deficit and disorder.

With these points in mind and on review of the mainstream developmental psychology literature on the autistic spectrum, children with the autistic spectrum label are reported to have difficulties across their social, emotional, language, and cognitive development. These areas will now be discussed.

Social and emotional development

To use the discourse of traditional developmental psychology, children labelled as on the autistic spectrum are deemed to have social impairments in a number of areas. For instance it is reported that they find it difficult to give eye contact, to engage in reciprocal conversations and to take part in conversational turn-taking (Frith 1989). They have little sense of social protocols, etiquette, conscience or personal modesty (Frith 1989) and are considered to have significant difficulties in engaging in

interpersonal social relationships (Jordan and Powell 1995; Bailey et al. 1996). There is an apparent lack of strong relationships with siblings or classroom peers, whilst interpersonal skills are described as abnormal (Trevarthen 1996).

It is widely agreed that children labelled with autistic spectrum do struggle in the social arena. However within a traditional developmental psychology model, social factors causing or exacerbating these difficulties are ignored, whilst individual deficit and disorder are strongly highlighted (Smukler 2005). This is evident in the following description of the autistic spectrum:

> The most characteristic social *abnormality* is the *lack of* social reciprocity and the *impaired* ability to develop loving relationships on the basis of interpersonal interactions. Social signalling and appreciation of other people's social cues are both *deficient* and there is a *poor* integration of social, communicative, and emotional features – as, for example, is expected in greeting behaviour.
>
> (Bailey et al. 1996, p.9, my italics)

As a result of Kanner's (1943) early observations, children medically diagnosed with autistic spectrum have often been considered to prefer their own company and to shun relationships with others (White and Roberson-Nay 2009). However more recent psychological studies highlight that these children report a desire for increased social peer interaction (White and Roberson-Nay 2009). For instance, using standardised self-report questionnaires, Bauminger and Kasari (2000) found that "autistic children" described greater feelings of loneliness than "typical children". The reported implications of this finding relates to a discussion of the cognitive versus affective basis of the autistic spectrum, rather than to the experiences of the participants themselves, particularly those of isolation. As such, and in seeking to fulfil the research aims, it could be argued that the voice of the children was marginalized.

A focus on emotional development within the developmental psychology field highlights findings that children with the autistic spectrum label lack empathy, do not show the usual interest in other people's emotional experiences (Frith 1989) and struggle to form emotional ties with others (Losh and Capps 2006). Their own

expressions of emotion are reported as inappropriate and / or overly intense and they are described as struggling to recognise or name their own emotional experiences (Jordan and Powell 1995).

In order to explore this area further, Losh and Capps (2006) examined the personal memory accounts of "High-Functioning children with Autism" using a discourse analytic framework. Although using a traditionally qualitative approach to language analysis, the framework employed for coding responses was quantitative in orientation and results were analysed statistically. Accounts of personal memories were compared between children with and without an autistic spectrum label. All participants were given a range of prompts containing single words relating to a range of emotions ranging from simple ("happy", "sad", etc.) to more complex (e.g. "proud", "surprised"). They were asked to give an account of a personal memory related to that emotion. The researchers report that the children with "High-Functioning Autism" provided appropriate accounts with regard to simple emotions, but their accounts showed a lack of understanding of more complex emotional prompts. Moreover the "autistic group" were considered less likely to personalise their narratives, tending to omit attributions of meaning to the events, and needing significantly more prompting to retrieve and narrate their emotional memories. As such, the researchers conclude:

> ...Autistic children's script-like emotional accounts, lacking reference even to the causes of their emotions, leave in question the children's depth of understanding of all types of emotional experiences.
>
> (Losh and Capps 2006, p.816)

It could however be argued that the somewhat clinical approach to eliciting personal memories of emotional experiences disadvantaged the children who were on the autistic spectrum. Memories were not accessed within the context of a natural conversation, and hence may have been harder to retrieve. The "script-like" nature of the research methods themselves may have been partly responsible for the "script-like" responses elicited, although there was clearly a difference between the two groups using the same methodology.

Psychological research also highlights that children with an autistic spectrum diagnosis suffer greater levels of anxiety than those without. For instance, in their research using semi-structured interview formats which were quantitatively coded and statistically analysed, Green, Gilchrist, Burton and Cox (2000) report that teenage boys diagnosed with "Asperger's Syndrome" exhibited significantly greater anxiety levels than those in the control group. In their similarly designed study, White and Roberson-Nay (2009) also describe elevated anxiety levels which correlated with greater reported experiences of loneliness. Again using a positivist research design, Bauminger and Kasari (2000) detail that "High-Functioning children with Autism" described greater feelings of loneliness compared to "typically developing children".

Language and communication

Some children labelled as on the autistic spectrum never acquire verbal language, whilst those that do speak are described within the developmental psychology literature as showing a range of impairments (Tager-Flusberg 2000). Expressive language is considered to be affected: For instance pronouns are sometimes reversed, there can be confusion over tenses, speech has a monotone quality and vocabulary is often delayed (Baron-Cohen and Bolton 1993; Jordan and Powell 1995). Language understanding is also reportedly impaired - often only understood literally (Baron-Cohen and Bolton 1993) - whilst the social and pragmatic functions of language are highlighted as poorly understood (Frith 1989). There is also considered to be a lack of skills for sharing joint attention (e.g. pointing and eye-contact) and this is described as predicting later language development (Mundy, Sigman and Kasari 1990).

The current study focussed on using a qualitative narrative inquiry approach to better understand the life experiences of young people with the autistic spectrum label. The developmental psychology field widely documents that these children show some impairment in their narrative skills. For instance difficulties described in narrating either a real or fictional story include a lack of contextual cues relevant to the listener as well as a tendency to add irrelevant details (Trevarthen 1996; Tager-Flusberg 2000).

As with the studies previously highlighted, much developmental psychology research into the narratives of children diagnosed with autistic spectrum label is undertaken from a positivist epistemological stance. There is an emphasis on the quantification of linguistic features and structures. The qualitative exploration of the narratives of life experiences of the children themselves is noticeably absent. For instance, Capps, Losh and Thurber (2000) used a quantitative content analysis approach to statistically analyse the narrative skills of children "with Autism" as they retold a fictional story. Although they reported some similarities in narrative skills across groups, the children "with Autism" were described as less likely than "typically-developing children" to use complex syntax structures in their stories, or to use evaluative features such as offering explanations of characters' thoughts and feelings.

Losh and Capps (2003) further examined the narrative abilities of "very high-functioning children with autism", again using a statistically-based content analysis approach. The ability of the participants to retell fictional stories was compared with their ability to tell real stories from their personal lives. Whilst the children were reported as showing relatively good narrative skills during the fiction-retelling task, this was apparently not replicated in the personal story-telling task. The children were thought to require considerably more probes and prompts to both initiate and maintain their personal story-telling compared to their fiction-retelling. These findings are discussed by the researchers with reference to improving autistic spectrum diagnostic procedures and are explained by the social and emotional deficits of the participants. Such conclusions are resonant with a medical and traditional developmental psychology focus on labelling and diagnosis as well as a child-deficit view of impairment. Again it could be argued that the voice of the participants themselves is silenced.

Goldman's (2008) similarly designed study also reported deficits in the ability of children with "High-functioning autism" to produce coherent personal accounts. Findings were interpreted as resulting from participants' lack of understanding of the social need for narratives around sharing personal experiences. The researcher concludes:

> The result was a string of unconnected experiences rather than a meaningful autobiographical story. These findings suggest that children should be encouraged and taught to share their life experiences in meaningful ways to others.
>
> (Goldman 2008, p.1987)

Whilst the recommendations of Goldman's study superficially overlap with the aims of the present study, the former are again based on a view of child pathology rather than on a desire to better understand the life experiences of the participants involved. Goldman's aim to "teach" such children to share their life experiences centres on a need to repair their impaired personal narrative skills, rather than to increase Goldman's own understanding of these children's lives. In contrast to this need to repair pathology, the current study aims to gain a more holistic view of how these young people see the world.

Cognition

Psychological research into the cognitive skills of children with the autistic spectrum label focuses on areas such as memory, sensory-processing, a lack of understanding of others' mental states and rigid, repetitive and obsessive behaviour.

With regard to memory, children with the autistic spectrum label are described as having good factual and rote memory skills. However as highlighted in Losh and Capps' (2006) research above, they are reported to struggle in recalling memories involving personal experience. As such, it is considered that they usually require direct questioning to prompt these (Jordan and Powell 1995). As highlighted earlier, it is deemed likely in the developmental psychology field that difficulties in remembering personal memories are linked to a lack of ability to reflect on emotional experience. It is considered this is because emotional appraisal skills are necessary to lay down personal memories (Jordan and Powell 1995).

Children medically diagnosed with autistic spectrum are also reported to lack an understanding of their own and other's mental states, known as a lack of theory of mind (Baron-Cohen and Bolton 1993). According to this theory, children cannot

appreciate that other people have minds which are separate to their own. The theory has been used to explain many of the social and communicative impairments linked to the autistic spectrum (Baron-Cohen and Bolton 1993).

As also reported in the developmental psychology literature, children labelled with autistic spectrum show either hypersensitive and / or hyposensitive tendencies with regard to sensory processing, although such tendencies are not included within the medical diagnostic criteria (Trevarthen 1996; Hilton, Graver and LaVesser 2006). It has been argued that these difficulties occur as a result of a very narrow attention span whereby incoming stimuli are not scanned for meaning, and thus choices cannot be made around which stimuli warrant attention (Jordan and Powell 1995). This inability to organise experiences into a coherent whole is known in psychology as the theory of weak central cohesion (Frith 1989).

A final cognitive style reported in the developmental psychology literature, is a tendency to develop repetitive behaviours, resistance to change as well as strong interests and obsessions (Bailey et al. 1996; Trevarthen 1996; Green et al. 2000). Moreover, some children labelled as on the autistic spectrum show isolated skills in areas such as reading, spelling, music or drawing even within the context of autistic spectrum - associated learning disability (Bailey et al. 1996). In rare instances very high ability in such areas is observed (Trevarthen 1996). Again as previously, all such features are viewed in the developmental psychology literature as symptomatic of pathology (e.g. Bailey et al. 1996; Green et al. 2000).

It should however be noted that such psychological research is useful in shedding light on some of the complex cognitive processes associated with the autistic spectrum, and to some degree does serve to increase understanding of the life experience of these children. However the psychological processes of forming and testing such theories either do not involve or include the views and lived experiences of the children themselves, or else only include them in relation to specific parts of the child. Additionally such processes do not place the issues in the context of children's lives nor do they consider the uniqueness of these children's experiences.

Conclusions

Medical and traditional developmental psychology models have their place in the modern world - advancing science and knowledge through research and experiments, discovering new medicine, and establishing causes and cures for a range of conditions including the autistic spectrum. However the disadvantages of such perspectives are also widely documented. The main criticism is their narrow focus on individual deficit (Lobianco and Sheppard-Jones 2007), whilst also creating a discourse of "victim" around individuals (Atkin and Hussain 2003). Such views offer us a limited degree of understanding of how children with the autistic spectrum label see their own lives. Moreover, medical and traditional developmental psychology approaches focus on a broad and sometimes diverse range of autistic spectrum symptomatic features, which has the effect of fragmenting the essential personhood of the children themselves. This results in "dehumanising" the children who are labelled (Smukler 2005:17). Through such discourses, these children are no longer seen first and foremost as whole and rounded people in their own right, rather as clusters of medical symptoms.

In ***Literature Review: Part Two***, existing literature on a range of social perspectives on the autistic spectrum will be explored. Finally in ***Part Three***, the limited research into the experiences of children themselves with the autistic spectrum label will be reviewed.

Part Two: Social Perspectives on the Autistic Spectrum

A Social Constructivist Perspective

In addition to disagreement within the medical field over its diagnostic criteria, there is further ongoing debate within even wider circles as to how the autistic spectrum should be viewed. For instance from a social constructivist perspective, Molloy and Vasil (2002:659) go so far as to theorize that "Asperger's Syndrome" is simply a "neurological difference" rather than a "disorder" as is commonly considered.

Social constructivist epistemologies encourage the dismantling of "dominant narratives" such as medicine in favour of the "fragmentary, heterogeneous and plural character of social 'realities'..." (Thomas 2007:36). Common social constructions of disability include notions of "personal tragedy for individuals so 'afflicted' " (Oliver 1990:80), or alternatively cultural constructions of "dependency" (Oliver 1990:81).

When adopting a social constructivist perspective, conclusions drawn from the assessments and diagnoses of powerful professionals (e.g. medics and psychologists) are also considered as social constructions (Gillman 2004), rather than as representative of the concrete external reality espoused within positivist epistemological circles. The dangers of a medical model view of diagnosis are highlighted, where medical labels threaten to overtake a person's identity, whilst the person beneath the label disappears (Gillman et al. 2000). The latter authors describe an alternative approach to medical diagnostic practices:

> Social constructionist ideas offer a way of thinking about diagnosis that challenges the so-called 'facts' and 'truths' that underpin and support it. If diagnosis is regarded as a hypothesis that is neither true or false, but more or less useful, then consideration could be given to the efficacy of specific diagnoses in terms of the opportunities they create or the possibilities they limit. Furthermore, viewing diagnosis as tentative or one of many possibilities affords those who are the recipients of diagnosis the choice to accept or reject it.
>
> (Gillman et al. 2000, p.405)

From an educational psychology perspective, Molloy and Vasil (2002) consider that diagnostic practices particularly within developmental disorders such as the autistic spectrum are unhelpful: Once a child is labelled, they lose their own unique identity in the eyes of others - with the diagnosis overshadowing all else. The child becomes the problem rather than the environment in which she finds herself (Molloy and Vasil 2002).

A Social Model Perspective

A social model of disability theorises that it is the existence of societal and environmental barriers which causes individuals to be disabled (Oliver 1990), rather than the impairment itself. Whilst social constructivist perspectives on disability centre on themes of social deviance (as expressed through society's distorted constructions of disability), a social model perspective is concerned with the social oppression of disabled people (Oliver 1990; Thomas 2007). However, as Hughes and Paterson (1997) describe, it could be argued that individual impairment receives scant attention within a social model, or is viewed medically within it. According to a purist social model perspective, it is claimed that there is "an untenable separation between body and culture, impairment and disability" (Hughes and Paterson 1997:326).

Theorists such as Goodley (2001), Hughes and Paterson (1997) and Corker and French (1998; cited Molloy and Vasil 2002) all argue for a "second wave" of social model theory, whereby impairment and disability are not segregated, rather both are viewed through a social and political framework. This allows for a view of impairment, which takes account both of the "lived experience of impairment", as well as its social construction within the wider discourse of disability (Goodley 2001; cited in Molloy and Vasil 2002:663). This view is of relevance to the primary aim of the present study, namely exploring the lived experience of the children who are labelled with autistic spectrum, within wider social, psychological and educational contexts.

Social Perspectives within Autistic Spectrum Research

As previously described there is a lack of research within the autistic spectrum field using social rather than medical perspectives on the autistic spectrum. In particular there is a lack of focus on the personal experience of the individuals – and particularly children - who are labelled. However, a social perspective on the autistic spectrum was used by Bagatell (2007) in his research with an adult labelled with "High Functioning ASD". Through the narrative analysis of Ben's identity development, his struggle against the dominant social discourse of "normality" and his accompanying sense of marginalisation were revealed. Some relief is subsequently found in a social group for adults on the autistic spectrum where Ben discovers an "Aspie" identity, which he celebrates by using car stickers and t-shirts bearing autistic - spectrum related slogans. In time however, Ben needs to learn to "orchestrate" the voices of this "Aspie world" with the "voices" of his everyday world – family, going to college, MENSA member etc., where the emphasis on fitting in with others and appearing "normal" remains (Bagatell 2007:423). By the end of the research, Ben is experiencing increasing difficulties around this process, serving as a reminder of the difficulties of living with the autistic spectrum label in a society where the dominant discourse is one of "normality".

Gray (2001) employed a social constructivist narrative inquiry approach to analyse semi-structured interviews with the parents of children " with Autism". His interpretation of the term *narrative* centred on themes of social discourse. Through this process he uncovered three possible narratives for the families in their view of the "Autism" diagnosis of their child. One was to comply with the "official narrative" of the Autism Centre (which favoured a medical model perspective of the autistic spectrum, involving treatment and therapeutic intervention); the second was a narrative of "resistance", where the parent became politically active in the autistic spectrum field; and the third was a narrative of "transcendence", where the parent turned to her religious faith to explain her child's "Autism". Whilst Gray's study is limited by a lack of exploration of the views of the children themselves, it is nevertheless useful in its social constructivist portrayal of a range of possible frames of reference aruound the autistic spectrum label.

There is also a dearth of empirical studies aimed at exploring the first-hand accounts of individuals labelled with autistic spectrum (Chamak, Bonniau, Jaunay and Cohen 2008). Although employing traditionally qualitative methodologies, earlier studies (e.g. Bemporad 1979; Volkmar and Cohen 1985) revealed an ongoing focus on deficit and disorder. These are akin to a medicalised "case-history" approach (Molloy and Vasil 2004:158), whilst the voice of the individual remains marginalized. More recently however, qualitative studies have been undertaken into the first hand Internet accounts of "High-Functioning Autistic adults" (Jones, Zahl and Huws 2001; Jones, Quigney and Huws 2003). Here thematic coding (Jones et al. 2001) and grounded theory techniques (Strauss and Corbin 1990; cited in Jones et al. 2003) enabled the voices of the researched to occupy a more central position, than within earlier studies of first-hand accounts. Moreover themes to emerge included feelings of isolation and difference, anxiety, depression and anger (Jones et al. 2001) as well as a range of unusual sensory experiences (Jones et al. 2003).

There is growing interest within the research field around the increasing number of autobiographies published by adults with the autistic spectrum label. Whilst ostensibly using qualitative methodologies, a number of textual analyses of autobiographies seem to employ a positivist interpretation of the autistic spectrum label, and findings are reported using a medical model discourse (e.g. Happé 1991; O'Neill and Jones 1997; Chamak et al. 2008).

Yet, it could be argued that autobiographies offer a completely alternative perspective to a medical one with regard to the autistic spectrum (Waltz 2005). For instance Smith (1996) uses social constructivism to reflect on the autobiographical publications of Grandin and Scenario (1986) and Williams (1992). Grandin's portrayal of the changing social constructions of the autistic spectrum over recent decades is emphasised, as well as her resistance to earlier psychoanalytic interpretations of her "condition". As Smith describes:

> Grandin structures her history as a history of negotiations with changing constructions of the autistic subject generated in the discourses of science and clinical therapy. Her narrative engages the ways in which the autistic is read – and misread – by the experts because it is the 'autistic subject' whom they see,

> and not the person with variable and changing characteristics associated with autism. In effect, Grandin invokes an everyday autobiography of her own to displace the everyday biography of autistic subjects written by experts.
>
> (Smith 1996, p.240)

Again from a social constructivist perspective and in her overview of the field of "autistic autobiography", Rose (2008) emphasises the autobiographies' portrayal of a society that disables and oppresses those with autistic spectrum differences, whilst their authors "simultaneously demand recognition of the different yet none-the-less entirely human autistic experience" (Rose 2008:49). Finally, Davidson (2007) undertook a qualitative textual analysis of a range of autobiographies also published by adults with the autistic spectrum label. She concludes that each text portrays a strongly unique and individual life, throwing into question the social tendency to construct those on the autistic spectrum as a homogenous group. Moreover, Davidson considers certain themes to be common across texts, including feelings of isolation and difference, anxiety and depression as well as unusual sensory experiences.

Conclusions

The preceding review reveals alternative social perspectives to those offered by medical and traditional developmental psychology models. It could be argued that such social perspectives are more ethical and respectful in their outlook towards those with an autistic spectrum diagnosis, as they seek to challenge processes that lead to the marginalisation of those who are different. However it is noteworthy that all the perspectives reviewed above – medical, psychological and social - share a lack of emphasis on the life experiences of children and young people considered as on the autistic spectrum. In the ***Literature Review: Part Three*** to follow, relevant research studies about the perspectives of young people themselves will be considered and implications for the present study discussed.

Part Three: The Young Person's Perspective

As already highlighted, there is a lack of research into the life experiences and perspectives of children and young people themselves with the autistic spectrum label. Of the research that exists, the majority is undertaken with children considered to be at the milder end of the spectrum, without accompanying learning difficulties or cognitive delay, and is usually conducted with a focus on mainstream educational experiences (e.g. Cesaroni and Garber 1991; Connor 2000; Humphrey and Lewis 2008; Camarena and Sarigiani 2009; Tobias 2009). It is noteworthy too that, to the researcher's knowledge, none of the studies are undertaken solely with young people: The perspectives of parents or other key adults and / or professionals are usually also included.

Earlier research by Cesaroni and Garber (1991) describing the personal account of a "High-Functioning thirteen-year-old boy with Autism" (and his parents) again uses a medicalised "case-study" discourse despite employing qualitative research methods. The research report lacks detail with regard to data analysis processes, however several emergent themes are highlighted: These include difficulties in sensory processing, good memory skills (in contrast to some findings in the medical / psychological literature), repetitive behaviours and difficulties with empathy and social interaction. The authors postulate that these unusual behaviours may mask a wish for human relationships, whilst they report a participant experience of...

> ...a growing awareness of being different from their peers and a strong desire to develop interpersonal relationships during adolescence. From an early age Albert has been isolated from his peers.
>
> (Cesaroni and Garber 1991, p.310)

Research with a Focus on Educational Experiences

More recently and from an educational psychology perspective, Connor (2000) undertook structured interviews about school with sixteen adolescents diagnosed with "Asperger Syndrome" from a range of mainstream school settings. School-based Special Educational Needs Coordinators (SENCos) were also interviewed. As with the previous study, this research is limited by its lack of data analysis process description, whilst the structured interview format does not allow for flexibility within interviews. However, student perspectives revealed social skills difficulties and anxiety around peer interactions, whilst participants also showed a good degree of self-insight into their own difficulties. Preferences for working alone in the school environment rather than engaging in group work were clear, as well as a desire to engage in individual activities at lunch-times, rather than socialising with other students.

Also from an educational psychology perspective, Tobias (2009) conducted two focus groups with pupils with an "Autistic Spectrum Disorder". These were located in the student support centre in a mainstream secondary school. A focus group was also conducted with participants' parents. A Personal Construct psychology approach (Kelly 1955; cited in Tobias 2009) was used as a framework for the student groups, designed to gain the young people's views on how they could best be supported within their school environment. Again teenagers reported difficulties in social interactions with peers and felt they were regularly the victims of bullying. As such they requested support aimed at increasing their sense of belonging within the school environment (including the continuation of existing access to adult mentors), as well as support to develop general life-skills, for instance in order to gain jobs once leaving school. With regard to the latter, Camarena and Sarigiani's (2009) semi-structured interviews into the post-secondary hopes of "High Functioning teenagers with Autistic Spectrum Disorder" revealed concerns that centred mainly around social rather than academic issues.

Humphrey and Lewis (2008) analysed semi-structured interviews and personal diaries, using an interpretative phenomenological approach. Their aim was to explore the perspectives on school of twenty young people "with Asperger Syndrome

and High-Functioning Autism" (Humphrey and Lewis 2008:23), between the ages of eleven and seventeen in four different mainstream school settings. A collaborative research approach was used with the participants, and student views of researcher interpretations were included as part of the data analysis. This was part of a wider study designed to enhance inclusive practice where the views of a range of key professionals within the schools were also explored. As before, students reported regular experiences of being bullied and teased, as well as associated feelings of social isolation. With regard to a view of their "AS" ("Asperger's") label, a number viewed themselves negatively and described themselves as "being different" or "not normal" (Humphrey and Lewis 2008:31). The young people also reported a desire to "fit in", suggesting they did not feel free to just be themselves (Humphrey and Lewis 2008:40), a finding which was also echoed in Camarena and Sarigiani's (2009) research where one adolescent described himself as being "on the edge of being normal" (Camarena and Sarigiani 2009:5).

All such studies share a focus on improving understanding of the educational experience of children labelled with autistic spectrum. However there is a paucity of research about how these children and young people view their lives as a whole. Biographical research focuses on gaining a deeper understanding of individual life experiences, whereby participants' own words and interpretations are used to create their life-story (Atkinson 1998). This approach has been used in research with children with physical disabilities (Curtin and Clarke 2005), as well as in the field of fostering / adoption (Ryan and Walker 1985, 1993) and childhood trauma (Rose and Philpot 2005). However, to the researcher's knowledge, only one such research study has been undertaken with young people labelled as on the autistic spectrum.

Molloy and Vasil (2004, the latter an EP) collaboratively created life-stories with six adolescents (four male and two female) who had been given the label "Asperger's Syndrome". Their parents were also interviewed and were present at the interviews with the young people. This was an international study: three participants lived in the UK and three in Singapore (with one Chinese participant and two British "expats"). One participant attended a special school for students deemed to be vulnerable to bullying and alienation, two attended the Special Educational Needs (SEN) unit of mainstream schools, whilst three attended mainstream schools.

Using the life-story research method located within a narrative inquiry framework (e.g. Goodley 1996; Gillman, Swain and Heyman 1997; Atkinson 1998: Traustadottir and Johnson 2000), Molloy and Vasil (2004) held conversations with the teenagers, using a broad topic guide covering a range of subjects including friends, family, interests, school as well as the impact of their "Asperger's" label. Life-stories were created using the young people's own words where possible, and initial drafts of the stories were checked and edited by all participants (teenagers and parents) in order to create the final versions. Researching from a clear social constructivist perspective, Molly and Vasil describe how....

> ..the life stories told by the adolescents in this book are not the objective truth but reflect how they see themselves and their experiences at a particular point in time. As they grow and mature they will understand themselves anew and will no doubt tell different stories about their pasts, which with each decade they will see in a different light.
>
> (Molloy and Vasil 2004, p. 27)

In terms of emergent themes within the life-stories, it appeared that issues around identity and diagnosis were most pertinent, although this was possibly reflective of parental influence within the research process. Most young people reported how they felt different from their "normal" peers whilst in one case, a parent considered her child was too attached to her "Asperger's identity", (Molloy and Vasil 2004). The young people described how they gained benefit from Asperger support groups, as they "took away the pressure of 'pretending to be normal' " and allowed them to make contact with peers with similar difficulties to themselves (Molloy and Vasil 2004:124). Teenagers also considered it helpful when they had been told about their diagnosis, as this helped them to understand themselves and their difficulties better. Socialising and making friends posed significant challenges for all adolescent participants. With the exception of one, all reported a strong desire for friendships based on close ties, and yet all struggled both to form and maintain such friendships. With regard to schooling, those who attended mainstream schools struggled with feelings of not belonging, whilst nearly all participants reported experiences of bullying and teasing. Although nearly all had hopes for the future with regards to

career plans, anger and depression were nevertheless experienced widely, often as a result of social isolation or being bullied by peers.

Clearly this research is pertinent to the present study: Findings are highly relevant to the primary research question of the present study, namely improving understanding of how young people labelled with autistic spectrum see their lives. There are also clear methodological parallels. However in contrast to the present study, the adolescents in Molloy and Vasil's research did not have associated learning difficulties. It is moreover noteworthy that parents were also interviewed, sat in on interviews with the teenagers, and edited the life-stories to ensure accuracy (Molloy and Vasil 2004). As such it is possible that the life-stories are not a complete reflection of how the young people saw their lives, as participants were not granted confidentiality or anonymity from their parents, and thus may not have spoken as freely as if they had been alone with the researchers. Sometimes it is not clear which is the voice of the parent and which the voice of the child. It could therefore be argued that there remains a need for research into the life experiences of young people themselves, where confidentiality is guaranteed and their own voice is heard. They could currently be considered as a marginalized group, whose voice has been silenced by the more powerful majority (Booth and Booth 1996; Atkinson and Walmsley 1999; Atkinson 2004), including professionals, parents and those not considered as on the autistic spectrum.

Some conclusions to ***Chapter Two: Literature Review*** will now be presented.

Literature Review: Conclusions

The preceding review highlights the limitations of a medical and traditional developmental psychology model in answering the two research questions of the present study. A lack of attention to the *lived experience* of the young people who are diagnosed results from an epistemologically realist concern with prevalence, assessment and diagnosis. Moreover, a focus on individual deficit and disorder ignores environmental and social impact and does not acknowledge the uniqueness of individual lives. In adopting alternative social views on the other hand, the medical model "grand narrative" is challenged, whereby medical diagnosis is considered a possibility rather than a "truth" (Gillman et al. 2000), and society's part in creating disabling barriers is also emphasised (Oliver 1990). A small number of studies with adults labelled with autistic spectrum have been conducted using social perspectives of the autistic spectrum. These and pertinent analyses of published adult autobiographies together hold promise with regard to improving understanding of individual life experience.

However the perspective of children and young people themselves is of greatest relevance to the two research questions of the present study. Themes emerging from their lived experience within the current limited research base include: A desire for interpersonal relationships coupled with difficulties in maintaining those relationships; experiences of being teased and bullied; feelings of anxiety, anger, depression and social isolation; a lack of "life-skills"; and finally feelings of "not being normal" coupled with a desire for information about their medical diagnosis to aid self-understanding. Some of these experiences relate to autistic spectrum impairments. However, in accordance with a social model view, the influence of society and its grand narrative of "normality" should not be underestimated. Indeed, in her autobiography about living with the autistic spectrum label, Holliday Willey (1999) expressed her wish for a society which...

> ...continues to break the boundaries of normal...and then, maybe then, the world really will welcome all people.
>
> (Holliday Willey 1999, p.75)

The implications of children's life experiences for EP practice will be fully addressed later in ***Chapter Ten: Conclusions and Implications for Practice***, in the light of findings from the present study. However in advance of this it may be useful to briefly note the following: When working within the discourse of medical and traditional developmental psychology models, EP assessment tends itself to be bound up with a focus on labelling and diagnosis, whilst EP facilitated school-based interventions centre on perceived deficits located within the child. On the other hand, when adopting social perspectives on the autistic spectrum, EP assessment and intervention seeks to improve the environment, whether at school, home and increasingly the community. Importantly for the current research aims moreover, there are EP assessment and intervention techniques specifically aimed at gaining the view of the child. These will also be discussed in the concluding chapter.

CHAPTER THREE: METHODOLOGY

This chapter provides a rationale for the methodology selected within the present study, followed by a description of its research methods and procedures. It then explores ethical and political issues and concludes with an examination of the data analysis process.

Methodology and Rationale

The exploration and representation of lived experiences of children and young people labelled with the autistic spectrum is scarce in the research literature to date. The current study is a step towards remedying this gap. The aims of the current study involved increasing our understanding of how young people who have been given the autistic spectrum label see their lives through the creation of life-stories. This was in order to better inform EP practice within the autistic spectrum field. These aims were operationalised (Cohen et al. 2000) into the following research questions:

How do young people with the autistic spectrum label see their lives and experiences?

How do these life experiences relate to theoretical models and disciplinary perspectives?

The primary aim and question relate to an increased understanding of the lived experience of others. As such, a research methodology located under the broad umbrella term "narrative inquiry" was considered (e.g. Reissman 1993; Booth and Booth 1996; Clandinin and Connelly 2000; Daiute and Lightfoot 2004; Clandinin 2007). The field of narrative inquiry incorporates effective research methods through which human experience can be understood (Clandinin and Connelly 2000).

Much of the research to date into the issues affecting young people labelled with autistic spectrum has been conducted from a perspective which views reality as an

objective, external entity (positivist epistemology). Within narrative inquiry, there is a different perspective on reality. In contrast to a positivist view, research methods within the narrative inquiry field are based on a view of reality as an ongoing construction by individuals reflected in, for example, the creation of their own life-stories (Roberts 2002). Here, reality is viewed as subjective and evolving, and the role of language is key within its ongoing construction (social constructivist epistemology).

In much of the research undertaken with young people labelled with autistic spectrum there has been a focus on a deficit model which is then generalised to other children who are regarded as a homogenous group (Clandinin and Connelly 2000). In studies such as these, the individual experience is lost. Narrative inquiry redresses this balance: As Pinnegar and Daynes (2007)) highlight,

> The particular deserves as much attention as the general among social scientists. Thus, as researchers, narrative inquirers embrace the power of the particular for understanding experience and using findings from research to inform themselves in specific places at specific times.
>
> (Pinnegar and Daynes 2007, p.24)

With regard to examining potential benefits for research participants, Booth and Booth (1996:59) consider that research methods located in the narrative inquiry field enable the "voice" of marginalized groups, such as those with communication impairments, to be heard. The critical feminist influence within narrative inquiry research methods is highlighted, where research is seen as "emancipatory" (Zarb 1992) and empowering for groups traditionally excluded from society. These transformative effects can extend to the researcher as well, who can also be personally changed through the research process (Roberts 2002).

Additional benefits were considered through selecting and using the "life-story" method for eliciting narratives by co-creating the participants' life-stories (Goodley 1996; Gillman et al. 1997; Traustadottir and Johnson 2000; Atkinson 2004). For instance, Atkinson (2004) describes how, when co-constructing the life-stories of a

group of adults with learning difficulties, a sense of empowerment and inclusion was experienced by participants as a result of taking part in the research. Moreover, Gillman et al (1997) consider that the process of creating life-stories helps participants to gain insights into their own lives, and is fundamental to having a sense of identity and self-concept.

From the perspective of narrative psychology (a branch of the wider narrative inquiry field) within which the current study is embedded, Crossley (2000) concurs that it is through the process of talking about and recording life-stories that individuals are "constantly engaged in the process of creating themselves" (Crossley 2000, p.10). Narrative psychology is considered to be "grounded in the humanistic tradition of understanding the whole child" (Korn 1997:35). Again linked to these humanistic psychology aims, narrative psychological approaches are increasingly used not only within the research field but also as therapeutic interventions, for instance as seen in the field of narrative therapy (e.g. DeSocio 2005; McLeod 2006).

During the earlier phase of the current study and whilst preparing for subsequent life-story work with young people, a small number of published autobiographies written by adults with the autistic spectrum label were read (Williams 1992). These were read with the view that the people themselves (adults, children and young people) who have been given the autistic spectrum label, are the experts on what life is like with it. Narrative psychology favours a view that the individual is the "expert" on themselves, rather than those in powerful professional positions such as medics, psychologists and psychiatrists (Crossley 2000). Through reading the autobiographies of diagnosed adults and in particular their portrayals of life as a child / teenager, it was hoped that a better understanding might be gained of the life experiences of the teenagers with whom I was soon to work.

In particular two autobiographies were selected for more focussed readings (Williams 1992; Holliday Willey 1999). However it should be noted that the authors of these autobiographies had either taken on or been given the autism label in adulthood. This was in contrast to the group of young people subsequently selected for life-story work, who had all already been given the autism label as teenagers. Moreover, the two autobiographies were set in Australia and America respectively,

whilst the young people with whom life-stories were created were based in the UK. As such it was not really possible to compare the perspectives and experiences of the published authors with those of the young people in the present study.

The two published autobiographies were subsequently used instead as a vehicle for experiementing with a particular narrative analysis technique, selected from the narrative psychology field. This technique focussed on specific turning points experienced by the authors as set against aspects of their socio-cultural environment. However, this narrative analysis tool was revealed as significantly limited. As such an alternative narrative analysis technique was subsequently selected to analyse the life-stories themselves, also taken from the narrative psychology field. This involved identifying dominant themes within the life-stories, as well as viewing them much more holistically. Further details of both narrative analysis techniques are presented under the ***Data Analysis*** section below.

Research Methods and Procedures

The current study was conducted in two phases. The first phase involved reading a number of published autobiographies, written by adults who have taken on the autistic spectrum label usually in adulthood. These texts were treated as "research data" and analysed accordingly. The second research phase consisted of direct individual life-story work with a small number of adolescents who had been placed in a specialist autistic spectrum school provision, and who had all been given variations of the autistic spectrum label.

Phase One: Autobiographies

There are now a number of published autobiographies, written by adults with the autistic spectrum label (e.g. Grandin and Scariano 1986; Williams 1992; Lawson 1998; Holliday Willey 1999; O'Neill 1999). It was considered that the perspectives of adults who themselves identify with the autistic spectrum label may provide an initial insight for the researcher into the young people's world (however possibilities

for this were limited as already described). Two autobiographies in particular were selected (Williams 1992; Holliday Willey 1999) because they focussed on late childhood and adolescent years, which were particularly relevant to the forthcoming selected group of young people. These were read in detail and analysed using a narrative analysis technique taken from the narrative psychology field (see under ***Data Analysis*** below for more details, associated limitations and a summary of conclusions).

Phase Two: Life Stories with Young People

Several stages of activity took place within this second phase of the current study. These included firstly selecting the participants, followed by planning the life-story sessions and finally undertaking the sessions themselves.

The Participants

It was decided that life-story work with adolescents rather than younger children would be undertaken, in view of the longer lives they had already experienced. Early decisions in the selection process included whether to work with young people labelled with autistic spectrum, who had been placed in mainstream rather than specialist provision. However on reflection, it was considered that the risks of these young people feeling "singled out" compared to their peers would outweigh the benefits of taking part in the research. It was hoped that young people in a specialist autistic spectrum provision were less likely to feel they had been selected as participants because they were "different" to their peers.

During the selection procedure, it was hoped that it would be possible to reflect a spread of gender, age and ethnicity. It was important that final participants would be in a position cognitively to give informed consent to the research. However the severity of their autistic spectrum impairment was not considered as an excluding factor per se.

Procedure

This phase of the study involved working individually with five young people, between the ages of twelve and fourteen, who had been given the autistic spectrum label and had been placed in a specialist autistic spectrum centre. All the young people were also labelled as having associated "moderate learning difficulties". Researcher access to the specialist centre was facilitated by the county Senior Educational Psychologist (Senior EP). This EP had responsibility for developing educational provision for children with an autistic spectrum label within the county and had close links herself with the specialist centre. The specialist centre formed part of a larger special school, and the latter catered for young people who had been given the general label "moderate learning difficulties" but were not considered to be on the autistic spectrum.

Next, an initial letter of information about the research was sent to the main special school Headteacher, and to the specialist autistic spectrum centre Manager (***Appendix 1***). Subsequent meetings were arranged between the researcher and the specialist centre Manager, and these were facilitated and also attended by the Senior EP. The purpose of these meetings was to explore the overall anticipated benefit of the research with the centre Manager, as well as to enlist her support and interest for the study. The centre Manager subsequently liased with the main special school Headteacher and both professionals gave written informed consent for the research to go ahead (***Appendix 2***).

The centre Manager proceeded to play a vital initial role in the facilitation of identifying young people who wanted to be included in the research. Letters of information about the research were sent via the Manager to the parents of all young people who, in the view of the Manager (who knew the children well), would be in a position cognitively to give informed consent to the research (***Appendix 3***). Out of a possible thirty sets of parents, this entailed letters being sent to twenty. Seven replies signalling initial interest in the research were subsequently returned.

All seven parents were contacted by the researcher by telephone in order to have an initial discussion about the research. A final group of five was selected by the

researcher to reflect a spread of gender and age as far as possible. Owing to the small sample numbers, it was unfortunately not possible to reflect a spread of ethnicity. Research packs were then sent out to each parent and young person, comprising of two parental consent forms (***Appendix 4 and 5***), an information sheet for the young person (***Appendix 6***) and consent form for the young person (***Appendix 7***).

Once selection of participants had been undertaken in this way, the planning process began for the forthcoming life-story sessions.

Planning and Undertaking the Life-Story Sessions

First, two informal visits were made to the specialist centre in order to make general observations and to consider possible approaches within the life-story sessions. It was important to attend no more than twice in this observational capacity, in order that the young people did not grow to view me as a member of staff at the school, rather than as a researcher. It was noted through observation that lessons within the centre included very visual teaching methods to which the young people seemed to respond well. This was taken into account when planning the life-story sessions and online research was subsequently undertaken into the availability of pictures, symbols and photographs, to be used as visual supports for the sessions.

When considering possible formats for the life-story work, ideally the young people would lead sessions as far as possible. They should decide themselves how they wanted to portray their life: For instance, as written text; as artwork; photographs; videos, etc. (Ibanez-Clark 2007; Thomson 2008). It was intended that the researcher role would be one of "facilitator" as far as possible. However, during conversations with parents prior to the sessions, it was highlighted that some of the young people might struggle with the concept of choice. Therefore plans were made to incorporate more structured approaches, where the researcher would take a greater lead in directing the session in the event of more open-ended methods being unsuccessful.

Prior to the sessions, three adolescent acquaintances (who the researcher knew personally) were informally consulted regarding the most important areas of their

lives. Following this, a list of key areas was drawn up to be used as a loose framework for guiding the life-story sessions (***Appendix 8***).

Narrative inquiry and life-story research literature was also consulted during this planning phase, and theoretical and practical ideas for the sessions were noted. For instance, Booth and Booth (1996) used narrative inquiry methods with young adults who had been given the label "learning difficulties", and found these adults had particular difficulty understanding the concept of time. In addition, Preece (2002), when working with children with the autistic spectrum label, found they had particular difficulties when recalling personal events. As such, consideration was given to how the temporal nature of the life-story could be visually represented to aid understanding during the sessions, if it transpired that this would be useful or necessary (***Appendix 9***).

Consideration at the early planning stage was also given to the role of questioning during the life-story sessions. In the same studies above, both Booth and Booth (1996) and Preece (2002) found that the young adults and children responded better to closed rather than open questions. Whilst it was important not to approach the sessions with assumptions regarding the individual needs of the adolescents, it was nevertheless useful to remember that questioning techniques might need refinement as the sessions progressed, if more open-ended forms of questioning were not successful.

In the event, I refined questioning techniques by making the questions more closed with regard to most participants. I used visual prompts with all participants during their initial session, to indicate the range of ways their life-stories could be created. However I employed more structured and ongoing visual approaches (***Appendix 9***) in only two out of five cases, whilst in both cases it soon transpired that the participants preferred to work without them. Hence, I only needed the loose framework referred to above as a guide for structuring the oral interviews, whilst using the photographs taken by participants (and in one case a video), as a stimulus for discussion.

The interviews were conducted with the following life-story research principles around researcher flexibility in mind....

> If you come with pat questions and follow them precisely in the interview, the answers will very likely be pat and only skim the surface. You should know when to depart from what you had planned and enter into a free-flowing conversation that will capture even more of what the person wants to tell you.
>
> (Atkinson 1998, p.32)

Between three and five life-story sessions were held with each participant, which usually lasted between forty minutes and an hour. Four out of five participants were keen to take photographs of key areas of their lives in between sessions to contribute to their life-story. However participants varied with regard to the number of photos they took and the prominence they gave them in their final life-stories. In one case, in addition to taking photographs, a participant also made a video of some aspects of her home life, which is not included for reasons of anonymity. A final participant in contrast just wanted to talk with me without using a camera or any other additional medium. All participants indicated they would like written life-story texts to be created. One participant wrote his own story during our sessions with myself as researcher acting as scribe. With regard to the remaining four participants, it was agreed that the researcher would create a rough written draft before their final session, and this draft would be used as a platform for collaboratively creating their final life-story with them (Atkinson 1998).

The researcher transcribed each interview immediately afterwards. Researcher reflections were recorded alongside and pointers for areas of questioning for the following session considered. Initial drafts were created from the transcripts using only the words of the participants themselves, with all the researcher's words edited out (Atkinson 1998). Sections of participants' words were moved around in order that similar content could be grouped under main themes which emerged from the transcripts (Atkinson 1998), such as "friends", "family", "school", etc. Participants had full control during the final session over the final shape of their written story, although they differed in the number of revisions they made to the rough draft.

It should be highlighted that participants were highly unique with regard to their individual needs as the interviews evolved and the life-stories were created. As such, further reflections on individual approaches used are included within the Researcher

Reflections contained in ***Chapters Four – Eight***, following the presentation of each life-story. A research journal was also kept and the notes from it used to develop my responses to the participants during our ongoing life-story work.

Having explored selection, planning and research methods considerations, an account will now be given of the ethical and political issues that arose during the research process.

Ethical and Political Issues

Political Considerations

Political considerations were particularly significant early on in the current study. As with all early research, it was necessary to promote the study to the different "stakeholders" within the process. Firstly, academic university approval was required. A research proposal was designed to fulfil university requirements for academic rigour and robustness, and ethics approval was obtained from the university for the study.

In addition to university affiliation, the researcher also worked as a Trainee Educational Psychologist (TEP) in the local authority where the study was to take place. It was important therefore that the relevance of the study, both academically and practically, was highlighted to psychology service colleagues. It was agreed at an early stage that the broad focus of the research should be on the autistic spectrum, primarily in light of a long-held interest on the part of the researcher in this field. The first formal meeting was held between the researcher, the Senior EP and specialist centre Manager.

At this meeting the nature of the intended study was both explained and promoted. In particular it was important to highlight the qualitative nature of this kind of research, where issues of validity, reliability and generalisation were different to those within the quantitative research paradigms. Anticipated outcomes and benefits of the intended study were clearly outlined. In particular it was necessary to

emphasise the potential for impact on service delivery of the lived personal experiences of the young people.

A final political consideration pertinent throughout the research related to the role of the researcher. From an early stage, it was particularly important that any information sent out to parents and participants about the research should be on university (rather than psychology service) headed paper. It was recognised that it would not be possible to eliminate issues of power imbalance between the researcher (as an adult) and the participant (as a teenager). However at the very least, the role of researcher, rather than Trainee EP needed to be highlighted. It was important that the participants perceived – if possible – the purpose of the sessions as one of inquiry and increased understanding for the researcher, rather than as psychological assessment or intervention for themselves.

Ethical Concerns

Before the selection of participants was undertaken, and with regard to seeking ethical approval from the university, there were a number of important issues to be considered. Firstly there was the issue of medical labelling, and the extent of the young people's awareness of the label they had been given. It was anticipated that this would vary amongst individual participants, as a result either of their age, the information they had been given by parents / other adults, and also on account of their individual cognitive skills. Therefore it was necessary at an early stage to consult the parents involved regarding their child's perceptions about the label they had been given. This information would then be used to act consistently where possible with the parents during the life-story sessions. Similar considerations needed to be given to the issue of specialist provision.

With regard to equality and diversity, gender issues would firstly be pertinent, as there may well be certain areas of their life that adolescent boys would not wish to discuss with an adult female researcher. It was therefore highlighted to participants that the researcher's role was one of facilitator, and the young person would lead the direction of the research. Further considerations included that the group would ideally reflect a spread of ethnicity, and anticipatory plans were put in place in this

regard: For instance, a discussion would be held with any participant from a Black or Minority Ethnic background regarding their background, in order that the message could be given that ethnic and cultural diversity was celebrated. However, in the final analysis all positive responses signalling initial interest were returned from parents of children of white British ethnic origin.

Informed Consent

It was vital that all those who were involved both directly or indirectly should give informed consent for the research to take place (British Psychological Society 2006). As described earlier, the centre Manager and the special school Headteacher were the first to give this.

With regard to gaining the informed consent of the participants and their parents, the first step involved telephoning those parents who signalled initial interest in the research. This was in order to explain the anticipated nature / content of the research to them first, including its purposes, anticipated directions, outcomes and wider benefits. The parents then played a vital initial role in helping to explain the issues to their child, as appropriate to their individual needs. Parents also advised the researcher at this stage whether the Participant Information Sheet (***Appendix 6***) was in a format which would be accessible for their child.

In addition and associated with their autistic spectrum label, the young people in the final group had also been given the label of "moderate learning difficulties". As such and for the purposes of informed consent, they were considered to be vulnerable. Ethical concerns included whether they had sufficient cognitive and/or communication ability to understand what the research involved. As described by the British Psychological Society (2006) psychologists should:

> Ensure that clients, particularly children and vulnerable adults, are given ample opportunity to understand the nature, purpose and anticipated consequences of any professional services or research participation, so that they may give informed consent to the extent that their capabilities allow.
>
> (British Psychological Society 2006, p.12)

With this in mind, following early discussions with the centre Manager, letters were only sent out to the parents of those young people whose cognition levels were such that they would understand the general purpose of the life-story sessions: This purpose was described as one where the researcher would understand better how the participants saw their own lives (See ***Appendix 6***). When designing the Participant Information Sheet, efforts were made to ensure it was written in plain English, and backed up with visual prompts. Moreover, as recommended by Marchant, Jones, Julyan and Giles (1999; cited in Preece 2002), the issue of informed consent was not treated as a one-off event, rather as an ongoing process throughout the research, in order that the young people felt free to withdraw at any time.

Anonymity and Confidentiality

Issues of anonymity are challenging when working with a small group from an individual school. Early consideration was given to how the letters were sent out in order to protect the anonymity of future participants as far as possible. Whilst positive slips signalling initial interest were passed via the centre Manager to the researcher, it was the researcher who ultimately chose the final sample from these to reflect where possible a spread of age, gender and ethnicity (although the latter has been discussed above, under ***Ethical Concerns***).

Also with regard to protecting the anonymity of participants, the Participant Information Sheet detailed how alternative names for the participants would be created, as well as for any other individuals they were going to include in their life-story. The name of the school would also be changed.

Finally and as described on the Participant Consent Form (***Appendix 7***), it was emphasised that the finished life-stories would belong to the young people themselves, and would be kept confidential by the researcher - other than when used anonymously within university research reporting activities (e.g. within the written thesis). The young people were of course free to show them to anyone they wished, however it was important for other adults not to make assumptions about this. It was particularly pertinent to highlight this issue to the parents involved, namely that their child may wish to keep their story private.

Researcher Reflexivity

As the current study involved working with vulnerable young people, it was especially important that the researcher maintained a reflexive approach to the research process as a whole, and to the life-story sessions in particular. Reflexivity is described by Etherington (2004) as..

> ...an ability to notice our responses to the world around us, other people and events, and to use that knowledge to inform our actions, communications and understandings. To be reflexive we need to be aware of our personal responses and to be able to make choices about how we use them. We also need to be aware of the personal, social and cultural contexts in which we live and work and to understand how these impact on the ways we interpret our world.
>
> (Etherington 2004, p.19)

Reflexivity within qualitative psychological research creates the opportunity for researchers to recognise their influence on interpretive accounts of the data (Etherington 2004; Payne 2007). It "bridges the chasm that more traditional research approaches created between the researcher and the researched" (Coyle 2007). Narrative Inquiry research methods promote the incorporation of the researcher's narrative, whereby personal assumptions are made explicit, and are considered to strongly influence all stages of the research process (Etherington 2004). Moreover, a benefit of narrative inquiry research is its focus on the individual life experience: This creates a situation where pre-conceived researcher assumptions are often challenged quite directly. However proactive researcher reflexivity ensures better access to life-story research data (Goodley 1996). Reflexivity is also considered to add robustness to research outcomes by making explicit the contextual situations out of which the data arose (Etherington 2004).

With regard to links between research and practice, ongoing reflexivity is increasingly considered an important component of professional educational psychology (Cunningham 1992; Evans 2005; Moore 2005; Pellegrini 2009). Moreover, it was important to remember that young people themselves have the capacity to be reflexive about their life experiences, with the potential to engage as

active agents and not passive recipients within the research process (Christensen and James 2001).

During the current study, it was especially important to maintain a reflexive approach during the collaborative creation of the participants' life-stories. A particular aim was that the young people should be given as much freedom as possible to direct this process themselves. However, as noted earlier, this approach may not feel comfortable for some participants, who may become overwhelmed by too many open questions, or by the concept of choice over life-story format. In the light of such possibilities, and remembering also there would be many other unforeseen events during the sessions, it was vital that the researcher endeavoured to maintain a reflexive approach throughout, in order that flexibility around participants' individual needs could be enhanced.

Reflexivity can be fostered through the use of research journals as the research is carried out (Etherington 2004). In order to aid the maintenance of these reflexive processes, a "research log" was kept from the outset in which the researcher recorded personal thoughts, considerations, emerging insights, as well as relevant notes from academic reading. The reflections were considered as "field notes" and subsequently treated as data within the narrative analysis process (Clandinin and Connelly 2000). These field notes are summarised within the ***Researcher Reflections*** contained in ***Chapters Four - Eight***, following presentation of each life-story.

Data Analysis

Phase One: Data Analysis of Published Autobiographies

As already described, two autobiographies written by adults who had taken on the autistic spectrum label (Williams 1992; Holliday Willey 1999) were read and analysed during the preliminary phase of the current study. Early explorations involved reading and re-reading each text. Initial literal readings developed into those which were more interpretive and reflexive (Mason 2002), whilst memos were also kept during the process (Robson 2002). The primary aim of reading these autobiographies was to gain a better understanding of how these adults saw their own lives, as a preparation for working with the individual young people to follow (although possibilities for this were limited as already described). In addition, it was necessary to trial a narrative analysis approach, in order to inform data analysis plans for the main study.

One of the aims of the current study was to seek to improve psychological intervention for young people who have been given the autistic spectrum label. In view of this a psychological approach to the narrative analysis of autobiographies was explored. A number of psychologists have used narrative analysis to analyse published autobiographies (e.g. Crossley 2000; Bruner 2001; Freeman and Brockmeier 2001; Harre 2001; Freeman 2004). These authors were consulted in order to gauge which narrative themes, in their view, commonly emerge from the genre of autobiographical writing. These were found to include the development of "self" as manifested by specific "turning points" in written autobiographical lives (Bruner 2001). The second theme - "socio-cultural environment" - was considered to inter-relate with this process of self-development (Freeman 2001). These two themes were used as a framework for constructing time-lines for each autobiography, against which specific turning points and important cultural and social environmental aspects could be plotted. Time-lines were subsequently compared and contrasted between autobiographies.

A full description of the narrative analysis of the published autobiographies, as well as subsequent findings, is included in ***Appendix 10***. Principal insights to emerge from the analysis included a sense of relief on the part of the authors to finally take on the autistic spectrum label in adulthood, coupled however with an ongoing sense of struggle around the dominant social discourse of "normality". Socio-cultural portrayals of highly negative attitudes towards people having the autistic spectrum label were also highlighted in sixties America and Australia. However it should be highlighted that the narrative analysis approach used was revealed as significantly limited: Through using the timelines (See ***Appendix* 10**, p. 222-232) as a framework for data analysis, the data became truncated and segmented such that the richness and depth of the autobiographies was lost, whilst a view of the texts as "whole entities" was also compromised. This arguably also had the effect of segmenting and categorising the very "personhood" of their authors, and no doubt limited possibilities for wider interpretation of the textual data sources.

As such an alternative narrative analysis approach would need to be considered for the main study.

Phase Two: Data Analysis of Life-Stories

1. Firstly it was noted that Clandinin and Connelly (2000) make the distinction between "field texts" and "research texts" within the narrative analysis process. The former texts include narratives, which are created collaboratively with the participants during the data collection process. The creation of the life-stories represented the "field texts" during the first stage in the narrative analysis process.

Several decisions were made during this first data analysis stage, as the collaborative creation of "field texts" in the form of life-stories took place between participants and researcher. These decisions included for instance how far the researcher should intervene in editing the "field texts" and how far they should be left to "speak for themselves" (Roberts 2002:46). As described earlier however, only the words of the participants themselves were used as directly lifted from the interview transcripts.

whilst the young people had ultimate ownership over editorial decisions as they revised and reconstructed the initial draft into their final life-story (Atkinson 1998).

2. A "research text" was written during the subsequent narrative analysis stage. This second stage involved transforming the "field texts" into a "research text", for the purpose of interpretation, analysis and discussion within the doctoral thesis. In undertaking this task, lessons learnt from the analysis of autobiographies (***Appendix 10***) were applied. Although still keen to locate the narrative analysis of data within the branch of narrative inquiry known as narrative psychology, this time I wanted to prioritise the holistic nature of the stories, in order that they could remain intact.

Upon consulting Lieblich et al (1998), it became clear that narrative analysis techniques can be divided into two broad groups. Firstly there are *holistic* techniques (Lieblich et al. 1998:12) and secondly *categorical* approaches (Lieblich et al. 1998:12). Techniques belonging to the former group focus on the life-story as a whole entity: Specific life-story sections are considered only within the context of the life-story as a whole. In contrast, techniques belonging to the latter group segment life-story data according to pre-defined categories (akin at times to content analysis). Taken to the extreme, such narrative analysis techniques analyse data quantitatively. Specific sections of the life-story are considered only in relation to other similarly categorised sections, and not in relation to the life-story as a whole.

Moreover within the *holistic-categorical* dimension, it is possible to focus either on the *content* or *form* of the life-story when using narrative analysis to analyse it. The former approach is concerned with what the narrator is saying and / or why they may be saying it. The latter focuses more on how the story is told, e.g. aspects of the plot, its relationship with the sequence of time, significant turning points, metaphor usage, etc. (Lieblich et al. 1998).

It could be argued that the narrative analysis of published autobiographies within the current study had focussed on their *form* rather than their *content*. For instance, attention had been paid to the chronological sequence of particular

"turning points", rather than to an interpretation of the actual content of those turning points. This had resulted in a kind of silencing of the **voice** of the authors. Moreover, through focussing on their *form*, the published autobiographies had become segmented somewhat akin to the *categorical* approach described above.

When considering implications for the narrative analysis of the co-constructed life-stories to follow, one of the aims of the current study was reconsidered, namely to redress within research the marginalisation of the **voice** of young people who are labelled with autistic spectrum. In light of this, it was important to really attend to the actual *content* of what they said. The current study also sought to treat the young people as whole human beings, and as such it was important that their life-stories should likewise be treated as whole entities. In contrast to a focus on *form* and *categorisation* as undertaken during analysis of the published autobiographies, a "*holistic – content*" narrative analysis approach was therefore considered more appropriate (Lieblich et al. 1998). As these narrative psychologists describe:

> The *holistic-content* mode of reading uses the complete life story of an individual and focuses on the content presented by it.
>
> (Lieblich et al. 1998, p.13, my italics)

3. Following the process described by these authors the stories were read and re-read several times, in order to gain a holistic impression both of individual life-stories, as well as an impression of the stories as a group. Next decisions were made around "special foci of content or themes" that were emerging both within and across stories and these were tracked within and across stories using coloured pens (Lieblich et al. 1998:63; Crossley 2007). These marked sections were then re-read as individual narrative themes both within and across stories (Lieblich et al. 1998; Crossley 2007). Selections of particular themes were made on the basis of "the space devoted to the theme in the text, its repetitive nature, and the number of details the teller provides about it" (Lieblich et al. 1998:63). However during this process, and commensurate with this kind of narrative analysis approach, it was important not to lose sight of the stories first and foremost as whole entities.

4. Dominant themes considered to emerge from the data as described were grouped together into the "research text", for the purpose of subsequent discussion and linkage to theoretical models and disciplinary perspectives. The same dominant thematic strands within the researcher reflections were also included as part of the "research text".

Conclusions

The purpose of ***Chapter Three: Methodology*** has been to provide a rationale for the choice of methodology within the current study, combined with a detailed account of the research methods and procedures employed. Ethical and political considerations have been discussed, followed by a description of the data analysis process.

The five collaboratively created life-stories will now be presented, each followed by their associated researcher reflections. The research questions of the present study will be directly addressed in ***Chapter Nine: Discussion of Themes*** and implications for professional educational psychology will be explored in ***Chapter Ten: Conclusions and Implications for Practice***. As a reminder and following Clandinin and Connelly (2000), it should be noted that the life-stories contained in the forthcoming ***Chapters 4-8*** were considered as "field texts" whilst their analysis and interpretation in ***Chapter 9*** is considered as the "research text".

CHAPTER FOUR: RACHEL

Introduction

Five life-story sessions took place with my first participant Rachel, all at her home. During our initial session, we discussed how she might like to make her life-story. As described in ***Chapter Three: Methodology***, various possibilities were highlighted to her, such as taking photographs, drawing, writing, making a book, etc. Rachel told me she would like to make a book, and that she wanted to do some drawings to go in it, with some writing underneath. When discussing the kind of book she would like, we agreed I would buy her a sketchbook. She was also keen initially to take photographs, saying she would like to include some of her new horse.

As the sessions progressed and aware of the constraints of our remaining time together, I suggested that in addition to her photos and drawing, I could use our transcripts to put a written story together using only her words. She seemed enthusiastic about this idea. As such, the fifth and final session was spent with Rachel editing and finalising the written text, which is included in full below. The photos that Rachel took, as well as the sketch which she drew, are included immediately after the written life-story below.

At the time of taking part in the research, Rachel was fourteen. Before we began our work together, her mother informed me that Rachel had a medical diagnosis of "Autistic Spectrum Disorder". However, on discussion with Rachel's mother prior to the sessions, it appeared that Rachel was not really aware of her own label, and her parents had not discussed it with her in depth. That said, Rachel's mother did explain to others the reason why Rachel didn't always understand things – "because of her condition", as she described it - and she told me that she did that in front of Rachel. Finally Rachel's mother considered that Rachel was aware that she went to a special school and that she was "different to others".

"Growing up with Horses": Rachel's Story

Horses

Some memories

Tina is my mum's horse. My mum had her when Tina was nearly three and she used to ride her when I was a little baby.

I can remember one black furry little pony. The fur was really thick and really curly. I was 3 years old, I think. We went down the little lane with grass on it. My mum ran forward and I was galloping. We were both laughing and then I went speeding past my mum. I don't know where he is now…probably still at the same farm just up the road from us.

I can remember another one that I used to ride - a really tall horse. It looked like a giraffe! It was a really dark horse and it always kept its head up really high. I didn't really like that horse, because it was always really scaring me. I was having a riding lesson up there and I was on the lead rope.

I can remember another one called Lucie. I liked her like so much that I really wanted her on loan. She was a chestnut mare.

One of my very old ponies was called Dolly. She was a little mare and she used to 'nap to the gate' but I got her out of it. I had her ages and ages ago, about a couple of years ago. When I had Dolly, there was only one tack room. Thieves nicked all the saddles and nearly all the bridles, apart

from my mum's double bridle that her mum gave to her. They didn't nick all the stuff but they nicked all the wheelbarrows. It was all nicked.

As Dolly's saddle and bridle had gone, we had to lunge her. A lunge is a long thick piece of string, which is quite long. This is used on horses so they do not go galloping off. Then we bought saddles for Dolly and Tina.

I had a chestnut boy called Kiz after Lady, I couldn't remember his real name because it was a really difficult long name. So I just called him Kiz then I had Patch, then Sky and now I have Berry.

Berry and Tina

Berry does not go galloping off, but he's a bit lazy. He's 'fit up' now.

I ride him now. He used to have loads of scabs on him because the other horses were bullying him. There are still a few on him, but not very many, as they're not bullying him anymore. When horses are new, they go into where the other horses are and they can get beaten up. So when Berry first went into the barn in with the other horses, I think they were out on the field. He went round kicking them all and they were kicking him back. They have stopped it now.

He had a few bald patches on his face, but they didn't go where the bridle was. He's got a really bad one, where the numnah goes over it. It's pink, but I don't think it actually rubs him. He's got another two on him but they don't really rub him either. He's also got one on the side of his face, but not very much and there's loads of hairs there now.

I got a new saddle because I don't really have one of my own. My mum is going to get some chains for it, because I don't want anybody to nick it.

I ride Tina sometimes, but we can't ride her at the moment because she's got a few scabs on her back where the saddle goes. It might rub on her back and it might hurt her, so we're just lunging her. It was something to do with wet and dry and it was spreading on her neck.

My mum does muck out, but Tina is out in the field all the time now. So my mum just brings her in, then lunges her and puts her feed out.

William Fox-Pitt and the Olympics

William Fox-Pitt goes to Badminton and he went to Hong Kong this year for the Olympics. They do really posh dressage there, with long striding and really short strides. They also do cross-country, that's really big.

They also do show-jumping which has jumps that are quite high. Normally I really like cross-country and show jumping, but I really like the dressage most.

A couple of weeks before, you get the dressage test. You have to practise it until you get it right. So Williams practises and practises it loads and loads of times, so that he doesn't do it wrong. If he gets it wrong in the dressage test, he gets penalties. So you have to practise it about a thousand times a day. They do it loads of times, so that they learn it and know how to do it. Then on the final day, they won't forget it.

You have to do sitting trot and in the dressage saddle, you have to wear really long stirrups with a bit of a bend in your knee.

They do the dressage on the first day and then cross-country and then show-jumping. For cross-country and show-jumping, you have to wear a show-jumping saddle and you have to bend over. You have to go with the horse because if you don't it makes the horse uncomfortable. So you have to go with it and give it some reign, so you don't hurt its mouth. Then, with your head, you have to keep it straight, like when you're sitting normally. You always have to keep your head forward and keep it up.

Horses and the family

I might be so passionate about horses because I have grown with them. It might have been my mum, I think she got me into horse-riding. My nan started horse-riding, but probably her mum started horse-riding as well. So it's in the family.

Friends

Primary school friends

My friends from primary school are in secondary school now, they are in R. [mainstream] Comprehensive. They are the same year as me, but they go to a different school. I never get to see them, but I never go outside very much.

I did have a best friend called Kelly at primary school until Bethan took her away. She was really nice and she used to look after me sometimes. When I got upset I didn't cry, but I did get a bit upset. She used to make me feel happy, and would make funny jokes and make something funny. I didn't mind that Kelly went off to a different secondary school to me at the end of primary school.

I also had a friend called Sean at primary school. He used to make me really laugh and used to make funny jokes. We used to bully one boy, a friend of mine called Bertie and we used to make him cry. I feel a little bit bad about that now. I was sad that Sean and I went to different Secondary schools. If I saw Sean again we would probably talk to each other and I would ask him about his school, R. [mainstream] Secondary school. I would also tell him about my school and that we do things like DT and Art.

Friends from school in my life now

My best friend is Oscar from the L. (specialist centre) school. I met him when I was in Year 7, when I started school. He's in Year 10 now, he's two months and one day older than me. He really makes me laugh and he tells me little jokes about friends.

I think he's started boarding on a Wednesday and a Thursday. I don't see him very much now because I moved into the main (special) A. school now. I wish I could see him more and have thought about inviting him over to the house. He did ask if I could come over to tea for one day, and my mum said she wanted to think about it. My mum would say yes,

but I don't know about Oscar's mum, I am not sure why she doesn't like him going to other people's houses. I have been to his birthday party.

I have all my friends in the main [special] A. school now. I met one of them in my taxi and then I met my other friend a few days after. Gradually I got more friends in the main school, so I really wanted to go there instead of the L. [specialist] centre. Most of my friends in the main school are really funny, especially my friend Graham. I like funny people.

I miss the rest of my friends from the L. (specialist) centre but I might ask if they can go to the main school as well. Chris is a friend from the L. (specialist) centre, and he is funny as well. I don't ever have my old L. centre school friends over to tea and if I could go to their house for tea I would. Oscar lives in Bumblehead and Chris lives near Dowdry, which might be too far away.

I made friends with some Year 11's last year in my taxi. They're in college now and in work. I have one of their mobile numbers on my mobile phone, so I can keep in touch, but I haven't talked to her for ages...

Other friends

I also have a friend called Amy. She 's from R. [mainstream] Secondary school in Year 8 or 9, I think. Sometimes she rides with me and sometimes she comes round here for a sleepover. We met at our yard, where we keep our horses. I don't mind that I am not at school with her, it's enough to see her at the yard. Amy and I talk about all sorts of

things – horses and stuff, and planning what we are going to do the next day. We don't talk about school. Amy and I used to sleep in the toy room when she first started coming over. Then we went down to my bedroom, and she sleeps on my bed. I sleep on the floor on a mattress next to her.

Sometimes other friends go skiing with us. My mum has known them for quite a long time. If we're going on holiday, sometimes we meet them on the motorway at a certain point.

The future

In the future we might move somewhere else, maybe Wales, or we might go down to Cornwall. This would be probably after college. I don't really want to move, because my friends are all here in Countyshire, so I just want to stay here.

School

Memories of pre-school and primary school

I can remember going to pre-school, it was really good. I have a video from pre-school, where we had to sit on this little car with a background behind it of the countryside. My hair was really long at the time and it was in two plaits. They had to take my hair out, it was all the way down my back. I had blonde hair at the time and when I washed my hair, by the morning I would have a blonde fringe.

I can remember a few bits of Primary school but not very much. I can't remember what I did on my first day, I think I just wanted my mum. But I can't remember. I went to that Primary school over the road.

There was a girl I did not like at primary school, her name was Bethan. She never wanted to go near me or anything, she didn't like me. I didn't really like her because she didn't really go near me and she took my friends away. She was a bit of a bully and none of the teachers or other children helped me with it. I don't know why she was unkind like that. I did not really mind and I just got over it but it was unpleasant at the time. She started to bully like that since I first came to the school. She was in my class and in the same year but we did not sit together. Because she took my friends away I used to play on my own but it was not difficult really and I managed.

I liked the Headteacher at primary school. He was funny, and he used to tell us all sorts of stories during assemblies. There weren't any teachers at primary school that I did not like, they were all quite nice.

I can remember my Year 6 Leavers' Service. We made a cup and it's downstairs at the moment. We coloured it with special stuff and then the lady burnt it. She may have burnt it before we coloured it with the special stuff. Then, during our Year 6 Leavers' Service, we had fruit pastilles in our cups. We had to sing during our Leavers' Service. I can remember a tiny bit of the songs but I can't remember what the lines were. I did feel a bit emotional on my last day, but not very much.

My school currently

The school I am in now is better than my primary school. I don't know why, I just really like it. I like the teachers. I have two favourite teachers: Our deputy headteacher and one of our school teachers. I don't know why I like the deputy headteacher, but I just like him. He doesn't really joke but he's just funny. I like one of our school teachers because he does DT with us. He's a really good artist. I just say 'I can't draw horses,' and he draws a horse for me. I don't know if there are any teachers I don't like at my school, most of them are in the middle.

We sometimes get homework at school, but not all the time. We get the work that we haven't quite finished, like drawing, and we have to take it home to finish it off. I don't mind having homework, but if there's hundreds of homework then I don't bother doing it. So sometimes I do my homework and sometimes I don't. They don't tell us off if we don't do our homework.

I am currently in Year 9. I know R. [mainstream] comprehensive school is probably a bigger school than mine, or they might be the same. I have been there with my sister and my mum, because my sister used to go there. I know they get loads of homework there.

I really like Art, DT and Swimming, but I don't really like Science, Dance or PE. I do Art on a Thursday which I enjoy. I have been painting a 'Wow!' picture using thick paint. It's about a 'bang,' that is blowing up. My favourite art materials are artists' drawing pencils, like my mum's.

In PE we have one group who goes off swimming and one group who stays at school and does PE. I am doing swimming again this term. I don't know why I don't like Science. We have to use Bunsen burners, and in our last lesson, we had to use toast in the bunsen burner...I burnt mine, though not very much, as it still had white bits. Two of my friends burnt their toast and one of them burnt the whole of it, it was black. I don't really like burnt toast, I really like light brown toast or dark brown toast.

I have moved into the main [special] R. school now. I wrote in my report - in the beginning or middle of last year - that I wanted to go to the main school, because I really wanted to go there. So I am no longer in the L. [specialist] centre. I moved when I came back from the summer holiday just for a whole day. Before the summer holidays I was staying there for half a day. Now I am there full-time, and it's really good, I really like it. I prefer it to the L. [specialist] centre, because I have all my friends in the main school. There is no-one in my school who is unkind to me, like Bethan was at primary school. They are all a lot nicer.

We do canal walks at school, which are 8 or 9 miles. Some people stay in school if they're not very good at walking, and do the "small walk" round the football field. Quite a lot of other people go on the long walk - the Year 8's, Year 9's, Year 10's and Year 11's. I did it last year. I had trainers on and my feet were really bad. Every time I do long walks, my feet get really tight and stuff, and they really hurt. I thought I was going to be comfortable in trainers, but they weren't as comfy as I thought.

My Family

My mum

My mum is a really talented artist, she draws some really good pictures. She's got watercolours and artists' colour pencils and she lets me use them if I ask her. She 's also got a red or maybe blue sketch book.

It might have been my mum who she got me into horse-riding. It might run in the family.

My dad

My dad is sometimes quite funny, but sometimes he can be a bit rough. He always wants to play play-fighting, but I don't really want to, so I just hit him really hard back. Then he hits me back but not very hard.

Sometimes my parents get me things that I really want, but not all the time.

Gemma

Gemma is my half-sister, we have different dads. My dad got married to another girl and my mum got married to another boy and they both split up and they met together. Then they had me. I was born when Gemma was seven. My mum had my sister with the other boy, so I'm always confused. I'm always thinking my dad is my sister's dad and my dad is my step-dad. I've met my sister's dad a few times on my sister's birthday, he's quite nice actually.

I used to play with Gemma, but when she went to secondary school she didn't used to play with me very much. As she got older in the years she had less time with me and had to do loads of schoolwork, so I didn't get very much time with her. I missed that at the time and I miss her now she's away. Now we kind of play with each other sometimes and I get to see her about twice a year. Sometimes we talk on the phone but not very much. I saw her in the summer holidays, as I went to Cornwall with my grandma and my granddad.

The thing I like best about Gemma is, when I'm sad, she always makes me feel happy again. She always gives me cuddles. If I saw her now I would probably play a board game with her.

My Grandparents

I have two granddads, but I don't see one of them. I last saw him ages and ages ago - I think it was last year and I only saw him once. He lives in a different country so he is abroad. He doesn't really want to see my mum,, I don't know why. He really likes the other children that he had, but I don't think he really likes my mum. So that's why we don't really see him.

I've seen my other granddad quite a lot, every time I go down to Cornwall I see him and I see my nan and her dog called Charlie every time I go up there. Charlie is the little dog that my nan has, he's getting really furry and getting really curly hair.

My nan is going to move house in Countyshire.

Cousins

I have nice cousins. Most of the time I don't really see all of them. I don't think I've seen one of them since I was a baby and most of them I haven't seen in years. Most of them live in Cornwall. I would like to see them more.

My family and the future

In the future we might move somewhere else, Wales or something or we might go down to Cornwall, probably after college when I'm older. But I don't really want to move, because my friends are all in Countyshire, so I just want to stay here.

I might just live with my Nan until I find somebody, until I find a house. I have not talked about that with my nan, I'm going to wait for a couple of years as we might not move.

My Pets

Jake

Jake was a dog who we rescued from the rescue centre. She got old and died when I was about five. I felt emotional about it. I was really upset and nearly crying. I still think about her now, but not all of the time, so it's still a little bit sad.

Sophie

We had Sophie before Jake died, and we have had her since she was a puppy.

She's really nice and cute and sometimes on her face she looks really cute like a big puppy. She's very gentle and soft and I just really like her. Sometimes when she's lying on the carpet in the living room and the adverts come on, I lie next to her and just stroke her, and sometimes I put my head on her. I think we have a special relationship. I really like her.

I really like walking with Sophie. I think it was last year when I was walking her and I was sitting down to have a drink. I had just finished when I saw a little head and I didn't know what it was. Then I saw it run across and it was a fox. I just recognised the head. I was feeling a bit scared but it was a bit far away for me to see. Sophie didn't really notice it.

Sammie

Sammie is my Nan's little dog. He is as nice as Sophie but when you first come in he just barks loud and for ages. He is as gentle as Sophie but not until he stops barking and calms down. He's getting really furry and getting really curly hair.

Future Pets

I'd like another pet but we can't have another dog until Sophie dies. We might have two dogs again - rescued dogs, like Jake was.

My Free Time

Holidays

I started skiing when I was about four or five and I find it really easy now. When I was a lot younger I was really nervous about skiing and I wanted to stay with mum. But now I'm fine.

We sometimes go skiing with some friends. If we're going on holiday, sometimes we meet them on the motorway at a certain point. My mum has known these friends for quite a long time.

Computers

Sometimes I play on my computer using computer games, sometimes I listen to music on my computer and sometimes I look at my pictures from different holidays on it.

My favourite computer games include my Laura Croft game. I haven't played it for a while since I've been ill. In the game we have to kill some tigers or they will kill you. I killed all of them, and the little monkeys and the snakes. I don't know how many I've got through now, but I still got a few left to kill.

Another computer game I play is one that's got all different colour balls that fall in. If you get three or more of the same colour, you can win points. I've also got a car racing game, called European racer. You race cars and there are a few police cars as well. I think one of the racers is when the police car chases you. I did a couple of races and I won them - I was in the British Racing Team.

I enjoy computer games because they have adventures. You can play all sorts of games, and they are always different, with different types of keys. We recently got Nintendo Wii and we sit downstairs now to play it.

My dad set me up on the Wii Fit. The programme does not have ages for children or teenagers, it's mainly for adults, so I'm aged twenty on it! All of us sometimes play on it and I enjoy it.

TV

I don't watch very much TV. I watch Heartbeat which is about coppers who try to get the bad people who are breaking in. Some of it is set in the country-side and some of it in the town. I also watch The X- Factor if it's on and the British got Talent, if it's on. The British got Talent has dancing, singing, all sorts of things, even dancing dogs! The dog was really good, it was standing up on its back paws. One of the judges said he had never seen a dog as intelligent as that.

We now have a TV in my dad's study in front of the exercise bike, so we can watch TV while we're exercising. My dad also bought a big TV for downstairs and it's about 37 inches. We've set it all up.

Music

I listen to music in the taxi on the way to and from school. I also listen to it in my room or on the TV sometimes.

My favourite music is a bit of Elvis Presley, Westlife, Boys Own and Rihanna. I've seen Shane Ward in concert in Swindon at the Oasis, which was really good. It was mostly all girls in the audience. I didn't know I was going to see him on live, I thought I was going to see him on TV. My mum told me about it, and I said 'Yes' because he's one of my favourite boy singers. Leona is my favourite girl singer. I really like one of her songs - the "Bleeding Heart" - and my mum likes her too. My dad's got her CD on the computer that I borrowed from my friend. I'm trying to get my dad to put it on to DVD, then I can hear the songs.

With regard to dancing to music, I don't like dancing with a dancing teacher. I like to dance the way I really want to. I would like to go to discos and nightclubs when I am older.

Other things I do in my free time

Sometimes I play in my toy room and play with a few toys such as my toy farm over there. I have a toy horse, as well as other animals for the farm. The toy horse has been professionally made and it's signed on its belly. I also sometimes read all sorts of books in the toy room, but not all the time.

I have a French sewing kit. My mum started me off with it and then I carried on afterwards, but I haven't done it for ages.

I don't go outside very much. I sometimes go out walking with my dog or play outside with my friend Amy, but normally I just stay in. In the winter I am always in because it's always cold. I don't know if I would like to go out more or whether I am happy staying in.

If I did go out more, I would like to walk around the fields on my own. I like it on my own. I don't know why, but it seems really nice to be on your own – and so I just like it. It's good to walk on your own because if you're scared of things, you can get used to them in the outside world. If I walked on my own at the moment, that would be a bit scary. For instance when I'm with cows, I'm really scared of them and yet, if I did it more, I'd get used to them. If I'm with my dog, I feel fine.

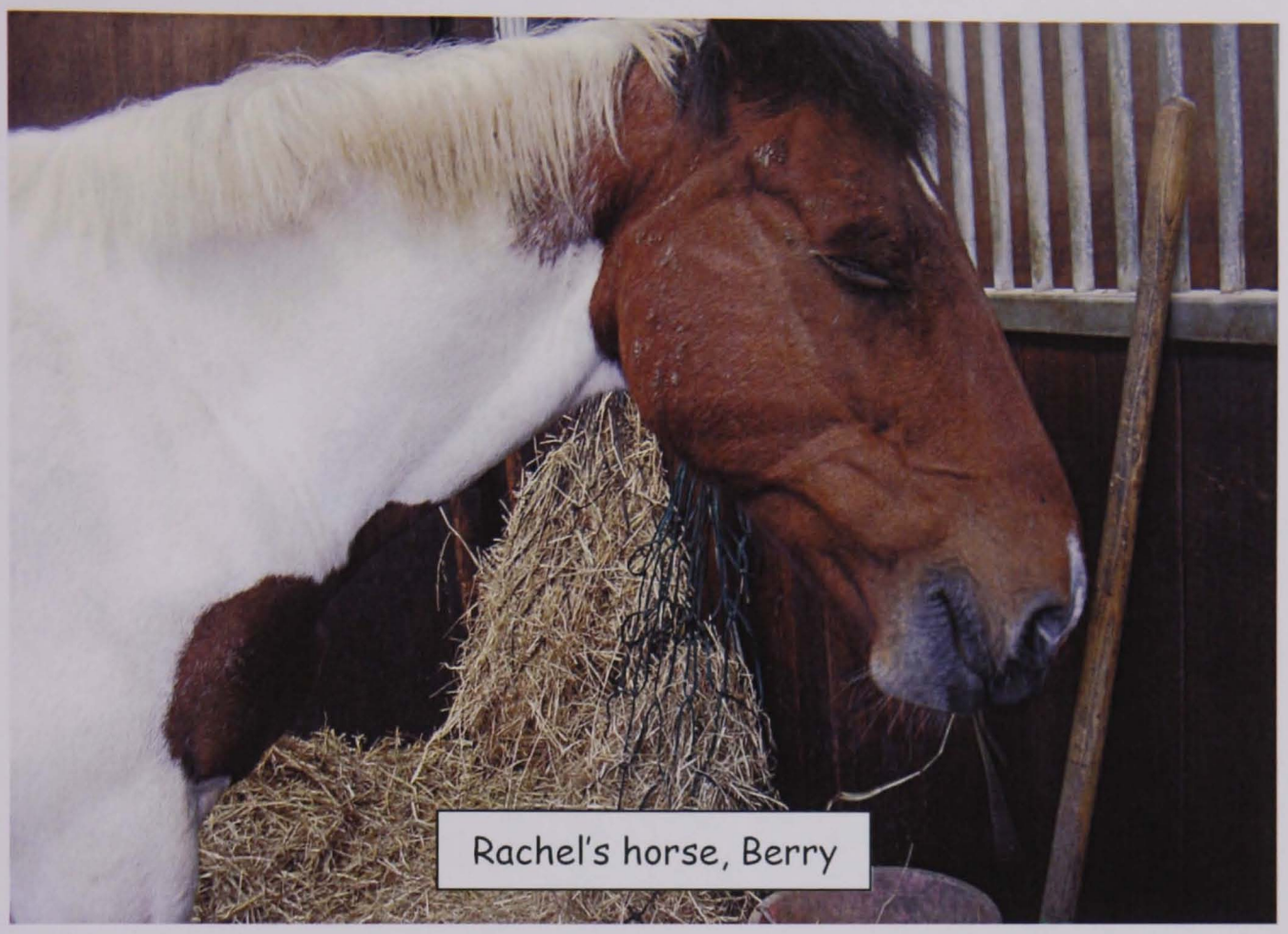
My home

I like being at home. My favorite room in the house is the toy room. I especially like the skylight windows in it. I have slept up there on my own and I like looking out of the window to see if I can see any stars. Sometimes if there are some out, I will see them.

When I was little this house had not yet been built. Back then we lived in Lipstee and also in Mincroft, as well as somewhere else that I cannot remember. We also lived at No. 4, Forehad for about eleven or twelve

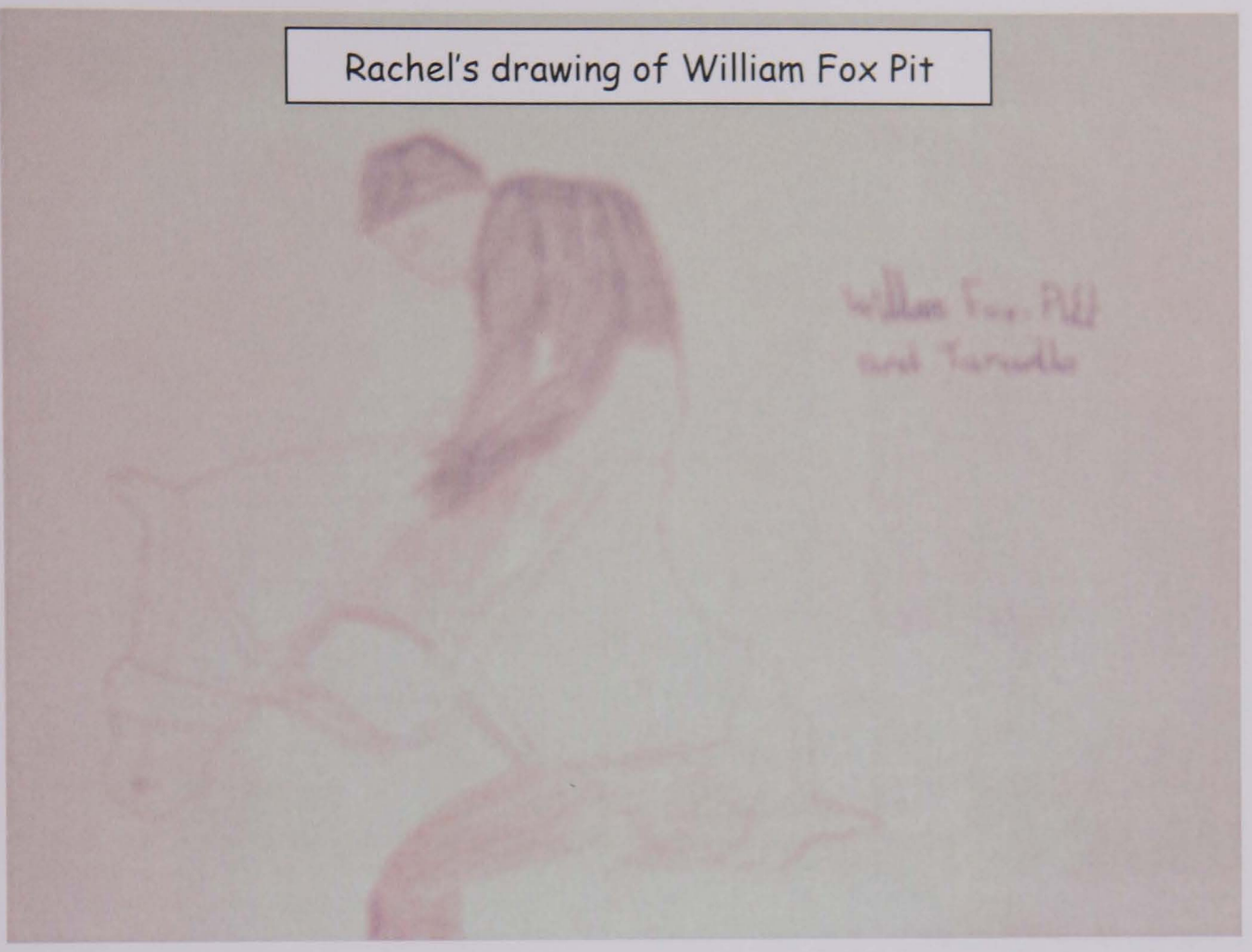
years. Then my dad started to help build this house, with a few other helpers.

Rachel's Photographs

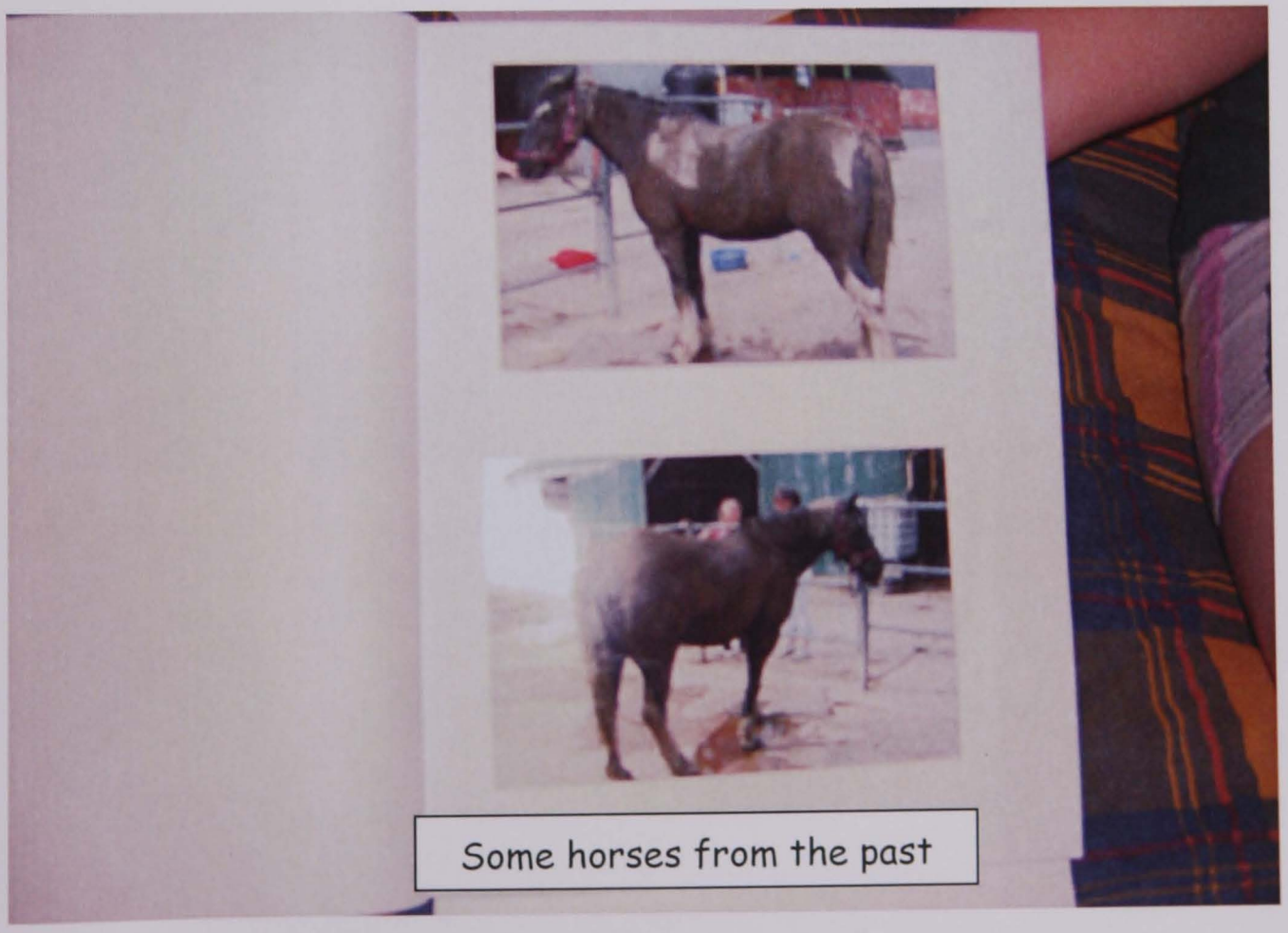


Rachel's photograph 1

Rachel's photograph 2



Rachel's photograph 3



Rachel's photograph 4

Rachel's photograph 5

Researcher Reflection

Rachel was my first participant. I was new to the life-story research methods and I had also never worked closely with young people who were in a specialist autistic spectrum provision. Additionally, my professional qualification was riding on the success of these sessions. As such, I approached my early work with Rachel with a degree of trepidation and anxiety.

On transcribing early recordings it was clear that my general anxiety was manifesting in a rather patronising tone of voice towards Rachel, as though I was talking to a much younger child. I also underestimated her abilities, for instance assuming she had difficulty with reading when later it became clear that she had reasonable reading skills. Upon supervisory discussion, it transpired that this attitude is also quite common towards people with learning difficulties and disabilities. I wondered if, for others as with myself, this was also on account of a fear of the unknown.

With regard to the life-story research method itself, researcher anxiety initially manifested in a focus on technology, e.g. concern over whether the digital recorder was working properly. Beyond the initial session, I then became aware of a tendency to avoid asking too many "probing questions", for fear of appearing overly interrogatory. Whilst an ethical mindfulness of this danger has its place, it was nevertheless possible that valuable opportunities were lost to explore important issues with Rachel as a result. For instance, in response to my question about her old friends from Primary school, Rachel replied "I never get to see them, but I never go outside very much". At the time, a decision was made not to follow this remark up, for fear of appearing overly intrusive (although attempts were made to explore it further in a subsequent session). In hindsight, further questioning following the remark would not have been inappropriate and may well have furnished useful information about Rachel's understanding and perspective on this aspect of her life.

Researcher concern over appearing overly inquisitorial was also particularly pertinent with regard to Rachel's autistic spectrum diagnosis. However, in this

situation, it could be argued that the concern held greater validity. According to Rachel's mother, Rachel was not really aware of her own label, as it had not been discussed in depth with her. It was important that as a researcher I did not give different messages to those given by parents and thus confuse the participant. On reflection therefore, I decided to try and tackle the subject indirectly, by discussing a display about the autistic spectrum that I had seen at her school, made by some of the students there. Interestingly, Rachel told me she had not noticed it herself, although she passed it every day in the corridor. She told me that the autistic spectrum had not been discussed within her year group at school, although it had been discussed with the year above, and that it was also not talked about in her family. I had a strong sense at that point that this was not an area she wished to discuss further and so we moved on to a different topic. Again in hindsight, I wondered whether my judgement had been accurate, or again whether it had been borne out of a misplaced fear of crossing a boundary. I also wondered what it is like for young people such as Rachel, when others talk about their condition in front of them but never say what it is.

In one sense I experienced confusion myself over whether the issue needed to be raised at all: The research question related to how young people with the autistic spectrum saw their own lives. If Rachel did not see her autistic spectrum label as part of her own life, then presumably it was my role as life-story researcher to represent her perspective. That said, the fact that her label had not been discussed at home or at school meant that this could be considered a "taboo subject", which may have left Rachel with some unanswered questions about herself and life. Whilst it was not my role to contradict approaches taken by home and school, part of my role was to explore Rachel's perspective on issues pertaining to her own life including her understanding – or lack thereof - of differences she may experience with regard to others.

The issue also raised in my mind one of the difficulties associated with the "invisibility" of a disability such as the autistic spectrum, compared to a physical disability. It could be argued that labels pertaining to "psychological" medical conditions carry more negative connotations compared to physical disabilities (Gillman et al. 2000). Had Rachel been in a wheelchair, it would have been much

harder to avoid the subject, both within our sessions as well as her own discussions with family and school.

As the sessions progressed my tendency to perceive Rachel as a younger child as a result of her label was soon challenged. For instance, and in contrast to the developmental psychology literature on the autistic spectrum reviewed earlier (Frith 1989; Bailey et al. 1996), she was quite able to give me eye-contact, to sit quite close to me and to engage in a conversation for up to an hour or more. She responded to jokes with smiles and was able take turns to speak within our conversations. In addition she was both a skilled and experienced horsewoman and skier. I was also particularly struck by quite a subtle aspect of Rachel's speech and intonation. She had a tendency when speaking to raise her voice a little higher at the end of her sentences, as is quite common among teenagers. I reflected later as to why I felt such surprise in this regard. I realised that, in view of her medical label, I had not expected her to exhibit subtle "teenage" characteristics such as this. It appeared that, on some level, I was allowing her medical label to 'screen out' the fact that she was a teenager and again I wondered how common this tendency was in others as well as in myself.

With regard to the life-story research method and in view of the fact that Rachel was my first participant, much reflection and learning took place with regard to the research method itself. In particular lessons were learnt over when to stand back from the process of creating the final life-story and when to take a more directive approach, with associated issues of ownership over the final product. For example initially, Rachel seemed quite clear that she wanted her life-story to revolve around sketches and photographs. She did draw one sketch and took a small number of photographs. However, although her photos and sketch did stimulate some discussion, the vast majority of our conversations took place independently of these, in a relatively natural and conversational way. As described in ***Chapter Three: Methodology,*** Rachel's life-story was eventually completed by using the words from our transcripts to create a story containing only her words. On questioning during the final session, Rachel told me she thought this final life-story was "really good". Whilst this response was positive, I was concerned in hindsight that Rachel had lost

some ownership over the final product, and that we had in some ways deviated from her original intention.

A further issue arose which was also pertinent to all five participants. This related to negotiating the location for the sessions, for instance whether they should take place at home or at school. Once this was achieved, it was then necessary to develop and manage my relationships with key adults in that location, yet at the same time operating within strict parameters of participant confidentiality. As the sessions in this case were conducted in Rachel's own home, it was necessary for me to also build a relationship with Rachel's mother, in order that she also felt comfortable having me there. On the other hand, it was also important that Rachel's mother understood that my sessions with her daughter were confidential, at least from my perspective (Rachel was of course free to share with others whatever she liked from our sessions). As I negotiated my relationship with Rachel's mother, I was sometimes aware of feeling awkward that she was excluded from a process involving work between her daughter and a relative stranger in her own home.

On a wider scale, it also highlighted to me how much harder it is to negotiate confidential access to young people compared with adults. Some of the reasons for this are of course valid. I was working with vulnerable young people and as such the protection of their well being during our work together was paramount. Additionally, there are more general issues to consider around child protection with regard to working with relative strangers. Upon further reflection, I also wondered if the concept of a confidential young person's "voice" was itself somewhat alien within the adult world, both with regard to the research field and even more so within EP practice. This issue will be discussed further throughout forthcoming chapters.

CHAPTER FIVE: LIZZIE

Introduction

Lizzie was my second participant. As with Rachel, the four life-story sessions took place in her home. When presented with a choice around how to make the life-story, Lizzie was very enthusiastic about taking photographs to stick in a life-story book, and she was also keen to make a video. (A selection of photographs are included immediately after Lizzie's final story below, however the video clips which were put onto DVD are not included for reasons of confidentiality).

Lizzie already enjoyed writing and drawing in her free time. She had previously completed several pieces of writing of her own, for instance about her school life, the autistic spectrum and favourite films. Some of her prior writing on school is included in her final story below, under the section ***School.*** In addition, Lizzie showed me some DVDs - made by the school and parents - about her early days at school, which also informed some of our discussions and subsequent final life-story.

As with Rachel, the final life-story was created from the transcripts of our conversations, using only the participant's words. Owing to Lizzie's enjoyment of writing and her writing skills, this approach was not considered until relatively late on in the process, as Lizzie would have been quite capable of completing written annotations of the photographs / videos herself with myself acting as facilitator. However, Lizzie seemed much more interested in looking at the photographs, and in talking to me and was less enthusiastic about my suggestions for writing activities. That said, by our final session, Lizzie had begun to make some short written entries of her own in the life-story book, both about the current run-up to Christmas at school, as well as about the medical condition of "autism". In effect, the book appeared to have taken on the role of a diary for her. Lizzie had also stuck in and labelled the photos that she had taken as part of our work together.

Unfortunately owing to time constraints, it had not been possible during the penultimate session to discuss and clarify whether Lizzie wanted me to put the fuller story together myself using the transcripts. In hindsight I realised this was an

important omission for which time should have been made. Fortunately however, on questioning during our final session, Lizzie was keen to include the fuller story in her book. As it was quite long, she suggested going through the story herself, editing it in her own time and then sending me the final version which she duly did. The final version as edited by Lizzie is included below.

At the time of taking part in the research, Lizzie was fourteen. Prior to her undertaking the research, her mother informed me that Lizzie had a medical diagnosis of "Autistic Spectrum Disorder", "Moderate Learning Difficulties" and "Tuberous Sclerosis". Her mother also told me that Lizzie was fully aware of her label, having discussed it with her family and at school. Lizzie herself told me that she was on the autistic spectrum, she had Tuberous Sclerosis and that she was sometimes slower at learning than others. Finally Lizzie's mother considered that Lizzie knew that she attended a special school, and understood why. However she felt Lizzie was currently feeling angry about being different to others and having to attend a special school, although despite this she did love her school.

"Learning about the Autistic Spectrum": Lizzie's Story

About Me

I drew a picture of myself and my personality when I was ten. In my picture, I coloured my personality yellow, because it is bright. My personality was the bright thing inside my outer shell.

I think I am really good and really loving. I like hugging people although I learnt at school that you have to ask if you can hug someone or they could feel uncomfortable. Sometimes I accidentally forget to ask and then I sometimes get a bit worried because the person doesn't like it. Sometimes I accidentally frighten them. I like helping people because it makes me feel good afterwards that I've made other people feel better. It also feels good when other people help me.

I am really good at writing, and I am also an artist. The problem with being an artist and a writer is that when you make books, sometimes the pages fall out and you have to put them all back in the right order again. I would like to be an artist when I am older, that's why I draw. I have drawn pictures of 'Harry Potter,' my brother, my cat, Pokemon as well as a really really really good one of myself, when I was thirteen. I have also written books called "Lizzie's Past," "The Land before Time," and "The Encyclopaedia of Autism" as well as books about my Primary and Secondary schools.

I think I've got self-control, but it can still be hard. I think it's to do with people's personalities and how much self-control they've got.

About my Autism

My parents found out I had autism when I was nine and they told me about it when I was ten.

Having autism means extremely sensitive ears. For example I don't like loud noises because they hurt my ears. Sometimes it gets too much. Noises that hurt my ears are loud drumming, dogs barking, and definitely thunder, lightening and fireworks. I'm a bit more used to aeroplanes now, although RAF's are still a bit noisy to me. If someone claps in my face, it always makes me jump. I am not sure if I want to go to church this Christmas yet, because of all the people.

I'm a bit more used to the sound of cars now but I'm still not used to vans and lorries. When I was at [mainstream] Primary School, at the age of ten, mum told me that the others walk on their own, but I couldn't because of my autism. I can't walk on my own because of the roads. When noises hurt my ears, I just get anxious and when I'm anxious I get quiet. Sometimes I wear ear defenders. These are round things, a bit like ear muffs but bigger and more helpful. Sometimes sounds are a bit louder to me. Sometimes noises are different to other people than they are to me.

There are other things I find difficult because of my autism. For instance when I go up in Prize-giving, I am not sure when to go up and when not to, after or before the person says my name.

Mum said it is because of my autism that I can draw so well. I also definitely find it difficult to know how I feel, for example, whether I am happy or excited, or sad.

Sometimes having autism isn't fun because sometimes people don't understand the way you say things, because you don't speak the same way as them. People my age normally speak using long words and I don't understand long words. Sometimes if someone is using a long word I guess what that long word means.

I find it hard to say if something wasn't my fault. I can't say long words I don't understand. Sometimes I say a sentence the wrong way. I can't really explain things properly either. And I struggle to get my words in the right order. Instead I say things backwards or the wrong way around. Another part of autism, is that you find it hard to cope with the word "no." I find it hard to cope with the word "no" sometimes.

The fun part of autism is watching cartoons and stuff. Because teenagers have normally learnt a bit more than me, they think they're more grown up. They think cartoons are for younger kids, not for people my age. I definitely know that because I have a friend called Michael who is fourteen, and he thinks that cartoons are for younger kids. But I enjoy them. I believe in God and I believe in things like dragons. My mum told me I think dragons are real, because of my autism.

One of my friends at school called Oscar, that bit's not part of his autism. I think its fun to believe things. Oscar likes to believe things that are real, from real life, rather than fantasy. I think it's fun to go on an adventure to find things out that you don't know if they're real or not. I like to go adventuring and stuff. Larry another friend from school is a bit of a fantasy type person. He said one day that he saw an ant as big as his pencil case! The teacher said that bit wasn't true. I thought it was funny.

Miss Robins, one of my teachers, finds out stuff about autism and she's good at remembering them as well. She said autistic people don't zip their coat up sometimes, because they don't feel the cold the way other normal people feel it. So autistic people don't get cold at the right times. I don't get cold. Once, when I was in the playground, I wasn't even cold and I didn't have a coat on! It was freezing cold and really cloudy and everything. I was really warm.

My sister doesn't understand me. I don't understand her because she's normal. My family don't have autism like me. I have a different brain to them. My family are all normal. They're all normal apart from my friend Ricky. He's the only one with Asperger's out of my whole family and friends outside of school. There's no-one with autism in my family or the rest of my friends. They are all normal.

At school my teacher taught me about the autistic spectrum. I have mild autism. Learning this was helpful because it means I can know autism, and also how much I've got. That also helps me to understand my friends better and it helps me understand myself better.

About my Tuberous Sclerosis

I was born with Tuberous Sclerosis with my Autism. I take a medicine that calms my brain down a bit and stops me from having fits.

My Schools

Primary school

It was fun at primary school sometimes, but I found it hard there because of the noise. There were lots of people. I liked to help people every day, taking them to first aid.

They didn't understand me properly there but they tried. I stayed out of some lessons and I didn't learn much in the classroom. I started to learn in Year 7 at [specialist] Secondary school. In Primary School it was complicated and I couldn't do it. I had to sit outside and do Numeracy outside the classroom. That's how I know that they didn't understand me because I didn't join in many lessons.

I only had one helper, Miss Franks. All the rest of the children were normal, except for my best friend Ronnie. He didn't get bullied either. There was one person called Diane, she used to bully me. She's the only person who did. But I was still nice to her even though she wasn't very nice to me.

Secondary school

When I was still at Primary School, Miss Evans the Head of my [specialist] Secondary school came to see me and watch what it was like. I spent time with Miss Evans and then I started to visit my Secondary School. Because of my disability I was going to [specialist] Secondary School. It was 2005 and I was eleven when I went for my first year to the Secondary School. When I first started in the September, I was anxious, shy and nervous. I think it was because it was my first time there and I didn't know anyone. First I was with my mum sat at the back at the class, on the visits.

I saw who was in my class – David, Carl, Larry, Oscar and Hal. They tried to help me and make friends with me.

I felt really nervous and anxious and I didn't talk. I also found it hard to say how I feel. The teachers tried to help me to speak. Because I was so anxious I had my 'Pickachu' that I held and cuddled, from the cupboard in the classroom. I had to have lots of help from the teachers and helpers. I didn't go to assembly, many lessons or anything and I cried and I got very upset, especially when loud noises happened. I got very anxious with changes. I sat at the back of the class on my first year.

I began to achieve with horses, dogs, joining in more lessons, speaking, loud noises, assembly, swimming to the deep end, and more. The teachers at Prospect Centre helped me to achieve these things. We went to Greatwood, with J. class, Miss Evans and Miss Maylin. The horses also helped me feel less anxious. I got filmed on the Greatwood

racehorses programme on channel 4. I was wearing a sticker that said something.

Prize-giving was in 2006 and I was 12 years old. I was very anxious and wore ear-plugs in my ears because of the noise. I had a prize. It was a trophy for my achievements with Miss Evans. It was my first time.

I was very anxious about the crowd and I sat at the front with the rest of my class. Miss Maylin had a board and helped me with my worries on the board. We waited and watched the leavers with Miss Evans. This was because I was anxious and Miss Evans was nervous too. I went to get a prize-giving book from someone. Then I went to get the trophy later with Miss Evans and Miss Evans and I went to sit back down.

Miss Evans taught me when I was in Year 7. She taught me a bit when I moved to a different classroom, and when we were only just Year 8. After that my teacher was Miss Tythe for Year 8 and 9. Miss Tythe was good. Miss Maylin is a jolly person who helped me go into assembly for the first time in Year 7. It did help and made a difference having her there. She was with me in Year 7 and Year 8. Then she left at the end of Year 8.

I also had my Sports Day. School wanted me to have my hair up because it grew a lot. I didn't like to have it up. It was my first sports day so I was nervous and anxious about what was going to happen and about lots of people. But I had fun.

At Christmas, I performed in a church with Jim, Tim, Sid, Pam, Mark, Arthur and more. We practised in Miss Evans's class. Miss Maylin and Miss Brown were all watching and helping as an audience. When I almost turned thirteen, we moved into a new building, a new Secondary school. In March it was Red Nose Day. We wore red noses and raised money for the council. In June we went to Pencelli. At Christmas I did another performance again in the church with Miss Evans and Miss Maylin.

In the holidays I turned thirteen. In September we moved into 9S, and we went on lots of trips like the great Weston Super Mare. In 9S my teacher and helpers were the same, but Miss Maylin left. In October we had a Harry Potter party, and I helped. We had potion-making, treasure hunts and a quiz and Miss Evans dressed up as a ghost.

Nearer to Christmas in November we had a school cinema with Harry Potter and Order of the Phoenix, or Ice Age Two the Melt-down as our choices. The choices for P5 was Harry Potter and P4 was Ice Age. Then we moved to Mr. Fyne's class for the next year and I turned fourteen. My helpers now are Miss Nicholas, Miss Tick and Miss Robins, and sometimes Miss Layley. My teacher Mr. Ben makes us laugh a lot, he's funny and now I have achieved a lot. In June it was Prize-giving. I won some sweets and a letter for achieving in boarding that I started in January. After half-term, I started lessons on Thursdays with Miss Layley (and her) dog, a black Labrador retriever, because I'm scared of dogs.

Once at school, we did about road safety. There was Miss Layley, Miss Brown and lots of teachers. The head of the secondary school was also

there and also there was a person we didn't know. The person knew all about road safety. We had a big map out and we had to do some activities that were for the younger people, so the teachers could see if they were suitable for them.

My class and I made up a story about dinosaurs and acted it out to the Year 11's. We all had the idea. We all made up the story. We wrote down how the story went and who everyone was. It took a long time. Then we had an idea that we could perform it in front of the Year 11's at assembly in the classroom. We just started practising the day before, so we didn't have very long. We were trying to be brave! Mr. Ben said the Year 11's loved it when I asked him what they thought.

Carl was the narrator, and he was saying the story and being a Time Traveller at the same time. Oscar was a Velograpter and a big Gigonotosaurus. David's the funny person, so he did lots of funny bits and added funny bits in the story. He had the idea of putting the pencil in my nose to make a dinosaur beak. Oscar was roaring in one of the bits of the presentation.

I gave my Christmas cards out to the teachers and my class.

My favourite lessons at school are Science, and RE. I like Science because I like learning about nature, and RE because I like learning about religion. We have swimming lessons on a Thursday, it used to be on a Tuesday when I was in Year 7 and 8.

Next year I'm going to be still in Year 10, and then I'm going to be in Year 11. So in 2010 I'm going to leave school.

Boarding

I started boarding in January on Wednesdays and Thursdays. For Halloween this year we had trifle and after tea, a Halloween party.

My favourite job I like at boarding is the recycling, because you can go into the playground, where the taxis are. I like it because there's a big plastic bag and massive big bins. I like trying to jump up and put it in and I like pouring the bin out. This is my favourite job because you can say hello to people who are walking around in the playground. You get to talk to them as well like with Miss Evans, who I saw once. You see lots of people and that's why it's my favourite job.

My Friends

My Class

When I got used to my class in Secondary school, I found out what everyone's personalities were like. David is very funny. He likes Dr. Who, Pokemon, Harry Potter and Scoobydoo. He is playful, good at drawing and is kind and friendly. Carl is funny, sensible, sometimes calm, helpful and kind. He likes Sonic Heroes, the Transformers and Harry Potter, and he's good at drawing. He can draw robots in 3D, it looks really good and real. Me and Carl have a different way of drawing. Oscar is good, playful, boisterous, kind and friendly and likes Pokemon, Harry Potter and wrestling.

The people in my class are all born with autism. The one who is more autistic is Hal who can't even speak properly either. Because of his autism, he doesn't join in lessons and he does other fun things instead. This is because he doesn't understand as much as us. Larry joins in lessons, but part of his autism is that he can't tell what's real and what's not. Carl has got a little bit of what David's got in his autism, but Carl can control himself sometimes. Carl and David still don't know when to stop and when not to, like I don't because of our autism. We don't know when to do things, at the right time. Oscar's autism isn't as much as mine and Carl's. Oscar says that cartoons aren't real and he's the type that doesn't believe things very easily

There's someone called Wilf in Year 11 as well, he's got autism, like David. Part of David's autism is swearing. Also, when you're a teenager, you say about ladies and that. This is because of his problems and he also copies stuff from comedy shows. David also finds it hard to cope with the word "No."

On the autistic spectrum, Oscar has a bit of autism. Larry and I have mild autism. David has the kind of autism that makes you silly and Carl would be that too. Carl isn't very silly, like telling jokes all the time. I'd say Hal's between 'severe' and 'very severe autism.' I can't tell because of how he acts.

I don't see these people from my class outside of school. Sometimes I think it is because some live far away.

Friends outside school

My friend Ronnie has Asperger's and he is my friend. He was in the same class as me in Primary School and now he goes to (mainstream) Secondary School. I still see him sometimes. He actually finds it really hard at JB. School now. He gets bullied because of his Asperger's. Ronnie would be a 'little bit of autism' on the autistic spectrum rainbow which would be just Asperger's. Sarah is Ronnie's sister. I don't see them a lot because they are busy sometimes.

Michael is another friend outside of school. I don't see him a lot, he lives far away. Catherine is Michael's sister.

I have a babysitter called Liane. She comes on Mondays, Wednesdays and Thursdays.

I like playing with kids. Michael and Catherine are only a little bit noisy. Other teenagers swear and stuff. That's why I say I like kids better because they don't know swear words yet. Kids play, and they're a bit calmer, and you can trust them a bit more.

My Family

My Mum and Dad

My mum is a nurse and my dad works with computers. When I first arrived at my Secondary school, my mum sat with me at the back of the class.

My mum and Lucy, my sister like shopping. They like Sainsbury's and Swindon.

My Sister, Lucy

One day I looked for Hebrew together with Lucy on the internet.

I'm a slow learner. I'm still learning what I would learn at Primary School in my new school.

My Brother, Alan

Alan is three.

My Free Time

Special interests

At weekends and holidays I watch TV. I've got DVDs like Pokemon, Harry Potter and Scooby-Doo. I also watch Sky which has better films and watch cartoons like 'The Land before Time,' and 'Pokemon.'

I also go on my laptop, my play station, and my DS. I also do drawing, and reading. I read and draw Harry Potter and Pokemon.

Pokemon is about a boy called Ash who gets his first Pokemon, and he wants to be a Pokemon master. A Pokemon is a creature with powers like electric shocks. There are electric types and flying types. They are big and small. They say there are 150 or more.

I don't like shopping.

My clothes

I like to wear Pokemon t-shirts and jumpers. I like to wear a shirt that's from the Tuberous Sclerosis club. It has the letter "S" on it and says Tuberous Sclerosis on it. I like to wear green t-shirts. I wish there was a t-shirt with autism written on it. One that says "A" and with autism at the bottom.

My Pets

My cat Suzie loves the towel, she likes to play with it. She guards it as well. If you touch it and she's guarding it, she quickly tries to get your hand and scratches it.

Finley has behaviour problems the vet said, so we need to give Finley attention and special food like my black cat Suzie.

I'm scared of dogs.

My Worries

Dogs

I'm scared of dogs. I started lessons with Miss X's dog, Larrie. This is helping me as I am getting to like her dog. I learnt that when dogs feel excited, their tail wags. Also I learnt that if you don't want a dog to sniff you, you put your hands in your pockets. Then your hands aren't there for them to sniff.

One day I saw a big dog. It was really fluffy and I could see the dog out of the window with an owner. He was very big but I don't know what type it was.

The Future

In 2010, I'm going to leave school. Mum said we're going to sort things out a bit more in the future.

Lizzie's Photographs

Lizzie's photograph 1

Lizzie's photograph 2

Lizzie's photograph 3

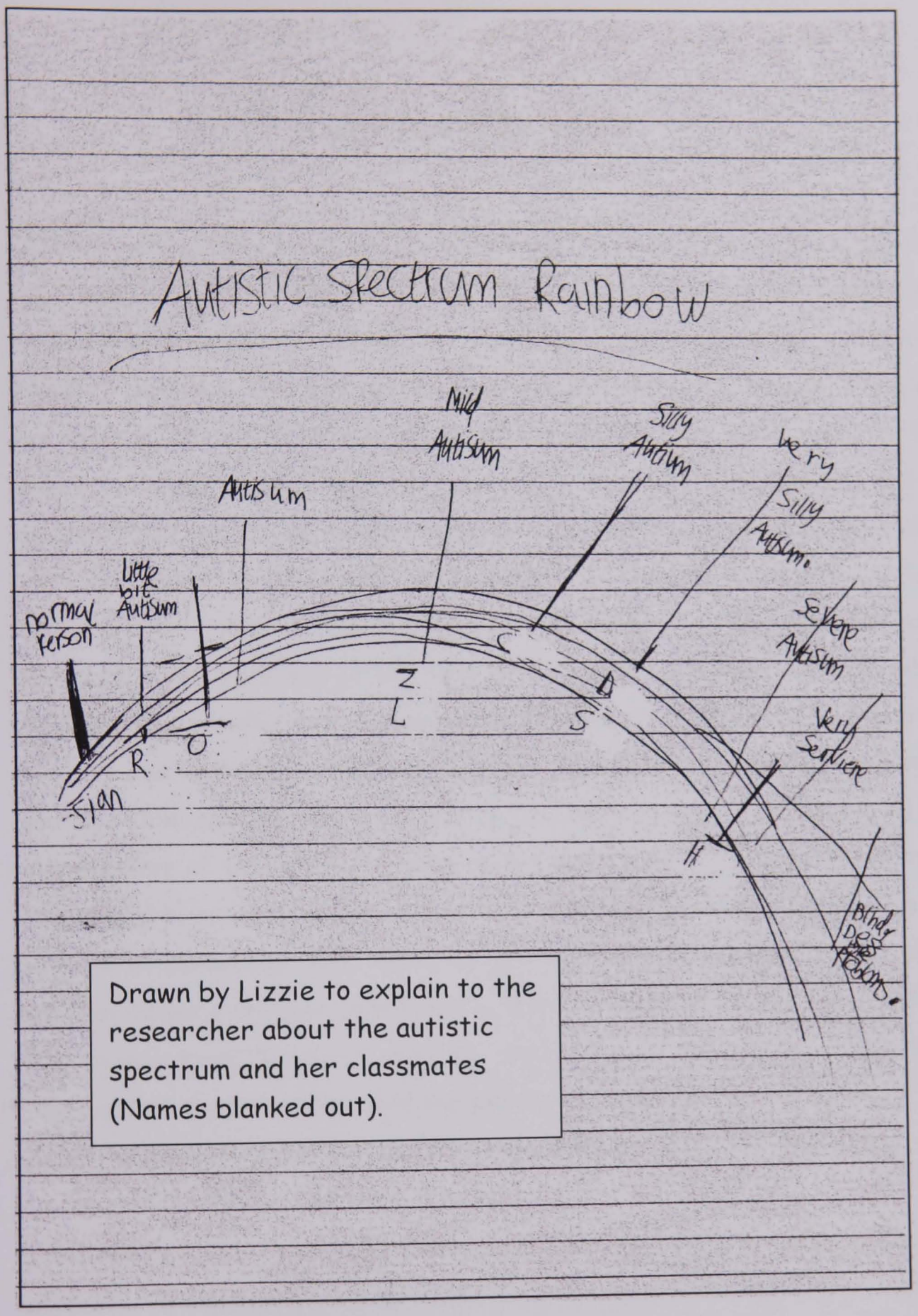
Lizzie's photograph 4

Lizzie's photograph 5

Lizzie's photograph 6

Lizzie's photograph 7

Lizzie's photograph 8



Lizzie's photograph 9

Researcher Reflection

From the outset of my work with Lizzie, I was conscious of lessons learnt from my work with Rachel, my first participant. In particular I was aware of my former tendency to be somewhat over-cautious in my questioning. Lizzie was much more proactive herself in directing the course of our conversations compared to Rachel. For instance, she herself brought up the subject of the autistic spectrum in the first session, a subject which clearly she knew a lot about and which seemed to be a special interest for her. In contrast to the previous participant, her autistic spectrum label was clearly a subject with which Lizzie was familiar, and which had been discussed openly with her both at school and with her family. Moreover, this time I was much more conscious of the need to follow up her remarks directly where possible. It is possible that this change of approach on my part, coupled with her openness and readiness to talk, led to our second session in particular being quite pivotal. From my perspective, it felt that the session significantly increased my understanding of Lizzie's perceptions around the effects of her autistic spectrum label, and gave me an awareness of a sense of individual and shared identity that she gained from having this label. From Lizzie's perspective, I wondered if the session had allowed her a valuable opportunity to share and "offload" some of her feelings and concerns to an "objective" outsider. By the end of the session I wondered if Lizzie almost over-identified with the autistic spectrum label, viewing herself and her classmates through this lens alone and forgetting the person behind the label.

At the outset of this session, Lizzie had asked me how much I knew about the autistic spectrum. In response to this question, whilst I told her I knew a little, I tried to convey to her that she was the expert on this and not me. In hindsight, I wondered if this approach had gone some way to encouraging her to reveal herself in the way that she did. More importantly however, Lizzie struck me as an extremely insightful and self-aware fourteen-year-old, which surprised me both on account of her age and - on reflection - also on account of her medical diagnosis. As previously discussed, during work with my first participant Rachel, I had allowed her medical diagnosis to

"screen out" the fact that she was a teenager. In a similar way with regard to Lizzie, I realised that her medical diagnosis had somehow in my mind precluded the potential for self-reflection and perceptiveness which Lizzie so clearly demonstrated.

Despite the pivotal nature of our second life-story session, there were nevertheless some associated concerns with regard to its direction. I became a little uncomfortable that an environment had been created which might have encouraged Lizzie to open up almost too much. Lizzie had shared some quite personal thoughts and feelings with me during this session, which she later deleted from her final story. Upon transcription, it struck me that the overall tone of the session had almost been reminiscent of a conversation within a counselling or therapeutic setting, rather than a research setting. In view of some of the issues that Lizzie was sharing with me, rather than trying to retain a detached researcher role, I found myself endeavouring to validate and empathise with her feelings and concerns, and in some instances to make some suggestions for how Lizzie could reframe her thinking in order to positively affect her emotional experience.

Whilst not a trained counsellor and mindful of the ethical pitfalls of assuming this role, my approach sometimes seemed more akin to my interventionist work as a TEP rather than as a researcher with a more exploratory agenda. As such the line between researcher and practitioner did not feel clear to me. In addition, had I been working purely in my capacity as TEP, Lizzie's feelings and concerns would have been fed directly back to parents and teachers, in order that intervention work could be planned. However, owing to the confidential nature of our work, this was not an option.

When editing her final story Lizzie decided to leave out a good proportion of the material arising from our second session. In hindsight it would have been useful to find out why she had done this (although this opportunity was missed as Lizzie had sent me her final edited down version by post). My sense was that Lizzie has chosen to omit certain parts of the story because she wanted to show the story to certain people in her life, and thus wanted to protect their feelings. This decision, whilst entirely valid, left me with mixed feelings. In my role as researcher, I felt a sense of disappointment that important data pertaining to a young person's view of life with

the autistic spectrum label would be "lost" from her finished life-story. However also in my role as researcher I recognised that the participant must have ultimate control over her final life-story (Atkinson 1998). My desire for a full and rich life-story could not become more important than the need for the participant to be an active agent in the creation of her story.

Final considerations took place around my developing skills with regard to the research method itself. As with Rachel, ongoing decisions centred around knowing when to stand back and allow Lizzie to take control, and when to step in and be more directive, for example in my questioning or with regard to creating the final story. In hindsight, I realised that Lizzie had been particularly enthusiastic about the visual methods for creating the story, namely using the camera to take photographs and make videos. She had seemed less enthusiastic when responding to my suggestions about accompanying such visual records with the written word. I was initially surprised at this, as it was clear that she was already a keen writer. However on reflection, as she already wrote in her free time almost as a "hobby", I wondered if undertaking more writing may have held less attraction for her in terms of novelty, whereas the camera in contrast did.

Interestingly I later realised that I was the one who felt uncomfortable about not having any written text, to accompany the visual records as "research data" and as evidence of our work together. Upon further consideration and supervisory discussion, it may in hindsight have been useful to experiment with an entirely visual approach to creating the life–story. It was possible that I had been influenced by a culture which places more weight on the written form, rather than on other ways of gathering data such as visual methods.

On the other hand, I was relieved that Lizzie appeared keen to include the version written from transcripts in her book and seemed happy to edit it herself, albeit in her own time. I hoped this meant that she had found the written life-story to be of value as well. In a sense, it did occur to me that perhaps the written version may have gone some way to creating a more "coherent whole" with regard to her life. It may have helped her to gain more insight into herself (Gillman et al. 1997) and aided her view of herself as a whole person (Korn 1997). Prior to our work together, Lizzie had

several separate pieces of writing relating to her life all completed at different points, which - as she said - had a habit of "falling out all over the place". Maybe now she had a life-story which brought those separate fragments together at that particular point in time.

CHAPTER SIX: CASSANDRA

Introduction

Following the choice about how she would like to create her own life-story. Cassandra originally told me she wanted to take photos, as well as make a book with writing in it. However as the sessions progressed, it became clear that Cassandra was keen to simply talk with me. Although she took some photos in between sessions, Cassandra told me that she had not really enjoyed taking the photos. We therefore agreed she did not need to take them and as such the photos are not included with her story.

We met for a total of four sessions at Cassandra's home, once a week, with each session usually lasting just over an hour. As agreed with Cassandra, a full story was produced by the researcher from the transcripts, which was condensed by the researcher into a shorter version in order for it to be fully accessible for Cassandra to change and edit as she wished. All attempts were made to include the integrity and essence of the longer version within the shorter version. The final accessible version as edited and finalised by Cassandra is included immediately below. The initial longer version was used for the purposes of analysis.

As discussed with Cassandra's mother, Cassandra had a medical diagnosis of "Asperger's Syndrome", as well as "Moderate Learning Difficulties". Cassandra was aware of this, having already discussed it with her parents. Her attendance at a special school had also been discussed between Cassandra and her parents. Cassandra had been given the explanation by her parents that she would not be able to cope in a different school.

"Becoming a Young Lady": Cassandra's Story

Growing up

I didn't like being a baby. I'm so glad I'm not two or three anymore. I'm getting out of my childhood and becoming a young lady and I'm enjoying that. I do want to grow up. It's not much fun being twelve. It's better now than when I was seven or eight because I've got more responsibilities, like looking after my clothes.

I started developing breasts when I was about nine or ten. In a couple of months, I'm going up a bra size to a 32AA. That's exciting because I want my boobs to grow. Me and my mum do 'mother / daughter shops.' I go to New Look and my favourite bit is choosing my new bras. I've had periods for a couple of years and they're always painful. They get on your nerves, it's just not nice.

I'm a bit worried about boyfriend and girlfriend because I don't want to start off too early. I think having a boyfriend will be fun because it's good talking. Also because it's love. I'm a bit too young for a boyfriend right now.

I'm obsessed with being pregnant, I'm very worried about it. I haven't learnt how to get pregnant yet. I would like a little girl if I was twenty-nine or thirty, once my life is sorted out.

School

I hated nursery school. It wasn't fun being at [mainstream] primary school either. You didn't learn about love and relationships and you didn't learn about how to get pregnant. I prefer my [specialist] Secondary school to Primary school.

There was a girl in my Primary school who got me to touch her bum. I had three friends at Primary school, called Zoe, Sarah and Katherine. I don't see them very much anymore. I wish I'd gone to B. [mainstream] Secondary school with them. I don't have many friends at my Secondary school. I like my Secondary school.

John is my best friend in my class. Also there's this nice boy called Graham and I've got a friend called Craig. There's a boy called Charlie who grabs me by the waist and he tickles me. I just want him to stop. The teachers have been getting cross at school because there's been a lot of bullying and swearing.

I'm the only girl in my class and I would like more girls in my class. I'm mostly friends with year 7 main school girls, like Suzie, Sophie and Cara.

There are some bullies in my school. Sophie keeps calling me nasty names and pulling my jumper. I think Suzie's becoming a bully too. I had a bit of an argument with Suzie and I'm not sure if we will get back together. I told a lie to my friend James. I said these girls picked on me when they didn't. I was in the timeout room all day. I was crying and I felt

very shaky. My teacher, Miss Evans really shouted at me. She was very angry, violent angry. She invaded my space.

We have SRE at school and I like it. I learnt about love, sex education and personal space. I haven't learnt about being pregnant yet. I want to learn about that. I have a boyfriend at school.

I like Miss Germaine at school, she's quite soft on us. I like Miss Evans but I don't like the way she tells me off.

I started boarding last September. I don't want to leave school. I think I'll miss it when it finishes. I'm not really sure what I'm going to do when I leave school.

About Me

I've got a disability called Asperger's Syndrome. I don't see the world like everybody else. I try and understand the way others see the world. I find it hard to fit in. I feel very left out when I am outside of school.

I get the giggles sometimes. I need to learn when to stop but it's quite difficult. I enjoy talking about things. I'm obsessed with hugging and cuddling people. I've got a thing about smells.

My Family

My dad's quite crazy at times. Once he stuck a jam doughnut in his face. I'd like my mum to have another baby, but she doesn't want to. I've got a

bit of an annoying brother called Chris. He's very cute, he looks good-looking and he smells nice. He goes out quite a lot. I also have a half-sister, called Amy and a half-brother called Nick. They're adults and they live their own lives.

Friends

My mum works quite a lot. She's very busy and she doesn't really have the time for me to play with my friend Craig outside of school. I never have any friends over from school. My mum and dad say no and it's unfair, because they live so far away.

Free Time

I like dancing, its good and I like Britney Spears.

My favourite TV programmes are Eastenders and Waterloo Road. I like Eastenders because its good and I'm learning about life. I've got a DVD called "Angus, Thongs and Perfect Snogging." It's about teenage girls. I've got a DS and I play "Cooker Mamma 2" and Dream Weddings.

I do trampolining club after school and it's good. I also do drama after school and its fun. When I come back for the evenings and weekends, I don't go out very much. My Auntie Vera has a dog called Mittie. Me and my mum take her out every Wednesday night.

I've been to a wedding reception and it was good. I was all dancey.

How I look

I have lots and lots of layers in my hair. My mum wants it tied up for school. She says at the weekends I can have it however I want.

I've got fifteen bottles of perfume. I like wearing glittery hoodies, short mini-skirts and strappy vests in the summer.

The Future

If I could change my life now I would I would like more friends. I would like a mobile phone and a boyfriend. When I learn to cope with my disability, my mum and dad say they will let me out on my own.

I told my mum that when I leave school at fifteen, I'm going to leave home. I would live with my friends. The thought of leaving school is a bit scary.

Researcher Reflection

From the outset of the life-story work with Cassandra, my developing relationship with her seemed even more pertinent than with previous participants. Cassandra was my third participant and as such had waited a few months before starting our work together. From the outset she gave the impression of being very keen to meet and work with me.

It soon became apparent that Cassandra was extremely interested in me. She regularly asked me questions about myself, sometimes of an extremely personal nature: These included questions around my own adolescent sexual development; questions relating to who I lived with; why did I not have children; what kinds of clothes and underwear I wore. It was clear on reflection that many of these questions were actually an attempt at understanding her own general and sexual development, a lot of which she clearly found confusing, as can be seen within the life-story itself. However some questions seemed also directed at gaining a genuine insight into my own life. In addition, Cassandra was particularly keen to gain my views on her life and development: For instance, she regularly (and sometimes repetitively) asked me whether I thought she was a child or a young person or adult. Leaving childhood behind and growing up was clearly a burning topic for Cassandra.

Cassandra asked such questions in a very focussed manner, sometimes leaving me feeling quite uncomfortable. Upon reflection, the experience gave me an insight into how participants might feel who are at the receiving end of interrogatory researcher questions. Moreover, although always conscious of needing to develop sensitive rapport with participants, Cassandra's persistent questioning nevertheless challenged a perhaps personal tendency as a researcher to maintain a degree of psychological distance from participants. Allied with this might be a perceived notion that the researcher is the person with the agenda and hence in control of the questions. As with Lizzie previously - albeit for different reasons - it was not possible to maintain this stance with Cassandra. She revealed herself as a focussed researcher in her own right, highly skilled in the art of penetrative questioning, despite the fact that she

hardly knew me. It was sometimes a struggle to shift the focus from myself onto her, in order that I could begin to gain an insight into her own life.

As described in her life-story above, Cassandra was clear that she enjoyed "talking things through" with people generally, and that she liked "having attention". She was also clear that she did not go out much once home after school, other than with her parents. She did not feel included by local teenagers in her street because of her Asperger's Syndrome. As a result, I had the sense that Cassandra really valued our time together, particularly as the sessions took place after school, which was a time when she felt particularly "left out". For instance, Cassandra would regularly check how much time we had left during our sessions, and would try and negotiate more time together. One week where she was clearly unwell, she still wanted to have the session, despite repeated offers on my part to return the following week. When I was absent for a week owing to illness myself, Cassandra told me that she had missed me. At the end of her written life-story, Cassandra included a sentence detailing how nice it had been spend time with me.

Again, whilst such comments were affirming on the one hand, they raised questions about my role as researcher, and how it is sometimes not possible to separate the researcher role from the role of "friend". I was also very conscious of trying to protect Cassandra's well-being as far as possible within our developing relationship, as it was important that her ongoing need for two-way communication with me was met as far as possible. However there were also the parallel demands of pursuing the research and addressing the research questions. The two requirements sometimes felt like competing agendas, almost akin to balancing two very different worlds, and I never felt confident that I had entirely succeeded in balancing both as the sessions progressed. In addition, needing to leave at the end of our work together, having begun to form our relationship, also brought a sense of discomfort.

A second theme emerging from researcher field notes related to the potential for researcher intervention, both directly in Cassandra's life in terms of child protection issues, as well as with regard to answering her many questions about sexual development. With regard to child protection, Cassandra told me about a recent event, which she did not ultimately wish to include in the final written life-story,

saying it was private. In view of this, the details are not included here. Cassandra also told me there was a boy in her class who "grabs me by the waist and tickles me". She told me she found this highly uncomfortable and wanted it to stop. Cassandra had already told her teachers about this boy, however at the time she did not feel this had particularly helped.

Both confidences (and particularly the first) raised important questions in my mind around child protection, and whether the information needed to be passed onto Cassandra's parents. Following ongoing reflection and supervision, the decision was made to check with Cassandra whether there was any action she wanted me to take. Moreover, if over time it became apparent that I would need to pass the information on regardless, I could give her the choice over who I told. In the event, Cassandra did not feel it necessary to raise either issue with other adults, and over time my judgement also was that this would not be necessary (she did not raise either issue again, and during subsequent sessions told me she enjoyed being at boarding school).

A related issue was Cassandra's questions about sexual development, and in particular pregnancy and how it happened, about which she was clearly very anxious. Again this highlighted the complexities involved in the role of the researcher and difficulties associated with trying to remain detached from a participant who clearly saw me as someone who could help her understand mysterious and anxiety-provoking issues. Following ongoing reflection, I decided to abstain from explaining reproductive issues to her, although I did give Cassandra suggestions about who she might talk to. I was particularly concerned not to contradict the approach taken by her parents, which might risk causing confusion for Cassandra, as well as causing difficulty for the family as a whole. Moreover Cassandra was very clear in her life-story that she was "obsessed with being pregnant", and she chose to read her whole life-story to her mother at the end of our final session. From her response to her daughter's written story, it was clear Cassandra's mother was already aware of her daughter's anxiety in this area.

However these researcher decisions were not clear-cut or easy to make. The issues served firstly as a strong reminder of my responsibilities as an adult working with a child, whether as researcher or as practitioner. Additionally I realised that my

response to the same situations as a practising TEP would very likely have been different to my response as a researcher. As a TEP, I either may not have seen this child again, or if I had, there would have been a significant time period in between. Within EP practice, and with regard to possible child protection issues in particular, there is no luxury of time to form a gradual professional judgement about the necessity of breaking a child's confidentiality. This is the case even when the child has requested that it not to be broken, as in Cassandra's case. Professionals have to err on the side of caution at all times. Consequently this left me feeling a little uncomfortable around my decision of non-intervention, as this was not an approach which was usual for me.

Cassandra regularly required my reassurance around whether the sessions would be kept confidential from her parents. She would often check whether what we talked about in our sessions were "our business". Cassandra was particularly concerned that our discussions about "hormones" and related sexual issues would not be divulged. She also needed regular confirmation that she was allowed to talk about anything she wanted. Cassandra differed from other participants in the extent of her need for this kind of reassurance around confidentiality.

As we moved towards the final session where Cassandra would edit the final written life-story, she repeatedly checked that she did not have to show her life-story to her parents. Upon my suggestion, Cassandra felt it would be useful to remind her mother that the life-story was her own and thus private, which I duly did with Cassandra present and listening. At the end of the discussion, Cassandra told her mother: "This is Cassandra's private story, Cassandra Milton with Asperger's Syndrome" (although as described earlier, Cassandra did finally decide to show her mother the story at the end of our last session).

Our discussions sometimes included content of a personal and sexual nature. Cassandra's repeated requests around confidentiality from parents - although entirely appropriate in view of the nature of life-story work and although ultimately revoked by Cassandra herself through sharing the story with her mother - nevertheless sometimes left me feeling uncomfortable and at times isolated in my role as adult listener and "confidante". As before, it highlighted to me the difference between

research practice and professional EP practice. In my professional capacity as a TEP, the child's view is often seen as key to intervention, and thus a lot of what the child says is fed directly back to teachers and parents in order to inform subsequent problem-solving. It is unusual that children ask for what they say to be kept confidential in this context. One effect within professional practice of "sharing the child's voice" with other adults is that any difficult or concerning issues for the adult can also be shared. Here however, as a researcher undertaking life-story work, confidentiality is paramount, hence it was necessary for me to hold and manage any feelings of discomfort as the work progressed. Cassandra's ultimate decision during the final session to share her story with her mother went some way to relieving my discomfort, as another adult was now sharing some of the issues. I had a sense that Cassandra was almost "reintroducing" her mother into her very personal life, and there was an associated sense of me "handing her back" to her mother.

However, Cassandra's decision to read her life-story to her mother did cause me considerable surprise, in view of the many discussions we had had around confidentiality. Upon reflection, I wondered if it had been more important for Cassandra to have the opportunity to exercise choice per se, rather than the actual choice itself being the important factor. I also wondered if Cassandra was marking her psychological territory, attempting to claim a "voice" in a world where adults made most of the decisions affecting her life, a world which – certainly as a TEP – I would have been part of.

CHAPTER SEVEN: FRED

Introduction

Fred, my fourth and penultimate participant had a medical diagnosis of "High-Functioning Autism" as well as "Moderate Learning Difficulties" as described by his mother. He was twelve years old at the time of the research. During initial conversations with Fred's mother, she told me that he was aware he had "special needs", and that he sometimes referred to himself as "Fred with special needs, a little chef who comes from Mars". His mother also described conversations where she had explained to Fred that he was different to his three siblings, had an "autistic brain", and hence did not have friends visit the house to the same extent as his siblings.

Moreover, Fred's mother voiced her concerns that the life-story research method may not be appropriate for Fred. "Like most children with autism, he is in his own world", she commented. Fred's mother considered that Fred would find it hard to understand the concept of me even wanting to do a life-story with him, as he found it difficult to understand how someone else saw the world. She was worried that he would not co-operate, and that he may become upset.

We therefore came to an agreement. Firstly I would work with Fred towards the end of the research time-frame, by which point I myself would be more familiar with the life-story techniques. Secondly, I would try one session with him to see how it went before proceeding any more. And finally, if from the first session the approach did not appear suitable for Fred, I would consider other methods of data collection instead.

In the event, three sessions took place with Fred, all lasting about an hour each. In contrast to the previous three participants, these took place at school rather than at home. This was at the request of Fred's mother, as she considered that Fred would be too tired at the end of the school day to undertake the sessions at home.

I was aware from discussions with his mother that Fred enjoyed using cameras generally. During our conversation at the end of our first session about the different ways Fred could make his life-story, he seemed enthusiastic about the photographic approach. As such, the story was put together by the researcher using only Fred's words, taken from the transcripts of our discussions specifically about the photographs Fred took. The story was checked and edited by Fred in the final session.

"Lilo and Stitch": Fred's Story

I really enjoy Lilo and Stitch. I've already made a book called Tom and Stitch. Sometimes I act out Lilo and Stitch to other people. Some people like listening to me. I like to act out the story without people asking questions.

Stitch is an experiment and he escaped to earth. He met a little Hawaiian girl called Lilo. Stitch learnt a lesson about how to be kind. Lilo and Stitch are finding the one true place where they truly belong. That's where their home is, where they live.

All the experiments are Stitch's cousins. Lilo and Stitch sometimes call them Ohana (this means family) and family doesn't get left behind.

Fred's photograph 1

About Me

I think I enjoyed being little. When I was little, I used to have long hair. I remember when I first had my tooth out. I once ate dog food and my mum didn't know. It was horrible.

I went to Bumblebee [mainstream] Primary School. It's a good school and I enjoyed it. The teachers were nice.

I find all my school lessons hard now. A boy in my class called Ed sometimes tells lies. Sometimes I wish the lie detector experiment in Lilo and Stitch was real because then the experiment would bleep when he told a lie. Sometimes the teachers don't believe me and Ed keeps saying 'Yes he did.'

I live in Townford, it's not that far from school. I like my bedroom. I don't spend a lot of time in there.

At home I spend time with my brother, sister and mum. I always watch telly. My sister usually watches TV with me on Fridays. When it's Friday we always have pizza and then popcorn and watch a film.

I like drawing but I am not really good at it. I just think ideas. I make drawings of the Lilo and Stitch cartoon. I made up some experiments. I coloured them and decided what they could be designed to do. I have millions of them.

I've always wanted a laptop computer.

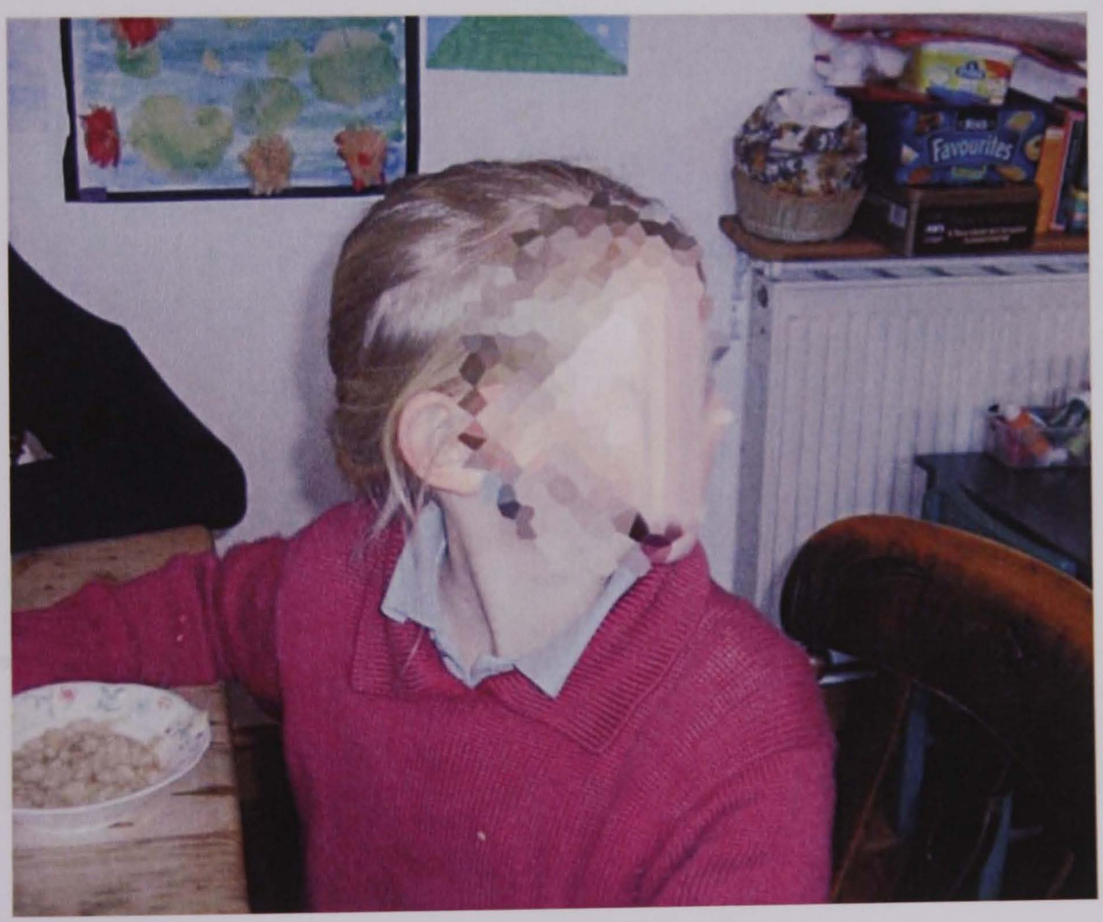
Fred's photograph 2

My Family

My brother is called Mike. My other brother is in London. Mike is about 16, I think. Mike is so kind to me. He is kinder than my little sister. Sometimes he cheers me up. Sometimes he teases me and makes me laugh.

Fred's photograph 3

My sister's name is Suzie. I think she is ten. She's sometimes silly. Once, when I was in the shower, she was speaking to me and she wasn't speaking. I said 'I can't hear you!' Sometimes I like her and sometimes we have arguments. Sometimes she cheers me up. Suzie goes to X [Primary] school. She has friends at her school and they come to see her at home. Suzie has porridge for breakfast but not all the mornings.



Fred's photograph 4

My mum is sometimes mean to me. She says nasty things when she is cross, if I did something naughty. She gets cross when I cry. I don't know what else to say about my mum.

Fred's photograph 5

Pets

My dog is called Jaffa. She's everybody's dog and she's my dog. She always listens to other people. Once when I went on a walk, I said to Jaffa "Jump over that tree log." She just jumped. I talk to her usually. I don't know what I talk to her about. She listens and understands.

Fred's photograph 6

My brother's pet snake is a nice snake. He doesn't bite, he's fine. Once I held him. I like having a pet snake in the house.

Fred's photograph 7

Fred's photograph 8

Researcher Reflection

On meeting Fred, I soon shared his mother's concern that the way I had worked with my previous three participants may not be suitable for him. Upon meeting me and listening to my explanation about the life-story, Fred told me he knew about stories and had made his own story-book about "Lilo and Stitch". This was a Walt Disney cartoon film about an alien who meets a little girl on earth, both sharing the feeling that they do not belong. By the end of the film, both characters discover the concept of family through which they learn to experience a sense of belonging. Fred told me that he had watched this film many times at home. Early on in our first session, he began to tell me about the story, responding to some of my questions about the film as he retold it. However before long, he asked if he could act the story out to me directly instead, saying he thought it was more interesting that way.

Although the majority of the first session was spent listening to Fred act out "Lilo and Stitch", I was able to negotiate fifteen minutes at the end to discuss with him the possibility of making his life-story. Fred responded positively to my suggestion about using the camera to do this, saying he thought he would enjoy it. Moreover, in view of Fred's enthusiasm to come back the following week, I decided to go ahead with the life-story research method as undertaken with previous participants.

Upon returning for the second session, Fred had taken several photographs as included above. However following a brief discussion of just a couple of these, Fred quickly asked if he could act out the second part of the "Lilo and Stitch" film to me. We negotiated that we would spend ten minutes discussing the remainder of the photographs, and we would spend the rest of the hour's session with Fred acting out the story. The third and final session followed a similar pattern: The first fifteen minutes were spent editing the final story on the laptop together, followed by Fred acting out the film for the rest of the time.

As Fred acted out the Walt Disney cartoon, he made it quite clear to me that he did not wish to be interrupted by my questions. On the occasions that I tried to ask a question about the story, Fred would become quite upset saying, "Please can you just

let me finish". I therefore soon learnt that I needed to stick to our agreement: Our time for shared dialogue would clearly be at the outset only. In effect it was as though Fred wanted me to be his audience only. It was notable that at the end of our sessions, Fred was often reluctant to return to class. It struck me this could either have been on account of finding his lessons hard (as described in his life-story), or that he was being given the rare opportunity of an "audience".

Following the end of our work together, I questioned whether I had been right to persist in persisting with the life-story research method with Fred, albeit in a condensed form. In view of Fred's enthusiasm about "Lilo and Stitch", it appeared that this story was a very important feature of his life. As such, I wondered if my approach should have been further adapted, using the story as a central framework for all our conversations. For instance, although I had obtained and watched the film myself at home, in hindsight it may have been useful for us to watch at least some of the film together. Questions could have been put to Fred about the characters, and attempts might have been made to link these with people in his own life. The emotional experiences of the characters could also have been explored, and again any connections with Fred's own emotional life might have been apparent. For instance a theme which ran through the film included feelings of "not belonging" in the world. This experience was particularly real for one of the characters who was an alien from another planet. In view of Fred's description of himself (reported by his mother) as "Fred with Special Needs, a little chef from Mars", I wondered if he might have identified with the feelings of "not belonging" which were portrayed in the film. I was disappointed to have missed the opportunity to explore this further.

Alternatively or additionally we could have made a video of Fred acting out the film, and / or collaboratively written the story of "Lilo and Stitch" to make a book. Again here, the video or story-making process may have served indirectly as a vehicle for questioning about links with his wider life.

During our sessions and in view of his obvious desire for an audience rather than someone to talk to, I had ample opportunity to observe Fred during our sessions. In particular I was struck by the difference in how Fred used his voice when he was acting, compared to when he was not acting. For instance when engaging in our

short discussions about the photographs, Fred spoke in a very soft and quiet voice which sounded like that of a much younger child. Yet when acting the story of "Lilo and Stitch", Fred tended to project his voice as though he was on stage. His voice would become strong, deep and often proclamatory in its tone. At other times and depending on the character, Fred's voice would become sharp and high, sometimes with a squealing tone to it. On occasion and according to the development of the story, Fred would even break into very loud and enthusiastic song. On watching the film between sessions, I realised Fred was offering me a very accurate impersonation of the different character voices he had heard.

At times, I found Fred's ability to "throw himself" into his performance and to have such a wide repertoire of voices a little disturbing. On reflection, it was the stark contrast between Fred's "usual" voice and his acting voices which proved unsettling to me at times. In addition, I noticed that Fred had memorised many of the lines correctly, reciting them as scripts which involved using some quite complex language. Again this represented a strong contrast with the language Fred used when he was not acting. At those times, the vocabulary he used seemed to be that of a much younger child. It felt as though I did not really know who the "real" Fred was, and this created a sense of confusion for me.

A final theme in my written observations of Fred related to my perceptions of the different worlds that he inhabited. When acting out the story, it felt to me as though he was totally absorbed in that world. I could imagine him running the visuals of the film in his own mind as he acted them out. His levels of absorption were such that, when another student started kicking our door very loudly from the outside as well as swearing very loudly, Fred did not appear to notice, carrying on with the story. At one point the specialist centre manager told us she was locking the door for our safety. Again Fred continued acting during and after she spoke to us. There had been a good degree of negotiation for even the small amount of time where I was allowed to share his world and discuss his life through the photographs he had taken. Even here I had the sense Fred was doing it for me rather than because he really wanted to. I was surprised to find during a fleeting moment in our second session, that I felt angry with Fred over this. I later realised that this was because I had felt dominated by his world, whilst my world felt squeezed out and my voice silenced.

On saying goodbye to Fred I had a sense that our work together had not been properly finished. I felt that he was not completely satisfied by the outcome. and neither was I. I also felt a sense of sadness that maybe we had not connected as fully as I would have liked, and that I had maybe missed opportunities to do this. That said, I was heartened by the fact that Fred said he wanted to keep the life-story, as well as the book I had bought him to keep it in.

CHAPTER EIGHT: LIAM

Introduction

Four life-story sessions took place with my final participant Liam, each lasting around forty minutes. On discussion with Liam's mother and as with Fred, she felt quite strongly they should take place in the school rather than home environment. In Liam's case, she felt there was a risk that he would feel threatened by an unfamiliar person working with him at home. Liam's mother also commented that he was quite an anxious young person, and I would have to work to "gain his trust".

Access to Liam was negotiated with his mother over period of about six months. Whilst she was initially enthusiastic for him to be one of the first participants in the research, there followed a period of emotional and behavioural difficulty for Liam. Liam's mother did not feel it was appropriate for him to be undertaking the life-story sessions with me as well during this time. As such Liam was included as a final participant, at a time when his mother felt he would be ready to take part.

Liam was fourteen at the time of taking part in the research. As described by his mother, Liam had a medical diagnosis of "Autistic Spectrum Disorder". He also had difficulties with reading and writing. His mother told me that Liam was aware of his label and his parents discussed it with him, although his mother was unsure about Liam's understanding of his label. She also highlighted that Liam understood why he went to a special school, namely that it was a school for young people with special needs.

On giving Liam the choice as to how he wanted to make his life-story, Liam said he "just wanted to talk". I offered him the opportunity to record some of our conversation in writing at a later point if he wanted to. He responded to this by saying "I might need some help with my writing". I took this as an indication that, although he felt he needed help, he nevertheless saw himself as engaging in the writing process. As such and in contrast to the previous four participants, Liam

wrote his story himself, whilst I acted as scribe and made suggestions where appropriate. This story is presented on the following page.

"My Free Time": Liam's Story

I like going out. I like shopping a little bit but I like Tesco's the best. I like buying foods that I like, like bread rolls, baguettes and burgers. I like buying orange juice and milkshakes. I like visiting shops, like DVD shops and I buy some DVDs. I choose the ones I want and I buy them. Dad takes me to the DVD shop.

I like going to the theatre to see the Chuckle Brothers. Some of the bits are funny. At the end of the show I sometimes get their autograph. Larry, Arthur (Larry's cousin) and Larry's dad came to the theatre too.

Larry comes over and we play on the Sims. Larry helps me with the Sims, and some bits I can do myself. I build the houses and move the furniture in. Larry makes the family. Sometimes I stay the night with Larry.

I like watching TV. I like watching Postman Pat, Fireman Sam and the Chuckle Brothers.

At school, lessons I like are DT and swimming. In DT, I make boxes and shelves and I take the boxes home to put things in it. Year 9's go swimming with the Year 8's. Lessons I don't like are music and dance. It's hard to do the dance moves. I don't like music because we do singing. I don't like the way I sing.

At home, my favourite room is my bedroom. I've got my TV, my game console and my DVDs. I watch these on my own. My pets are cats. They are called Lucy and Dylan. I like them. Lucy talks a lot. Dylan claws on the sofa, he's the young one. I choose my own clothes and I just wear any clothes. I think my mum goes and buys my clothes.

Researcher Reflection

As highlighted by his mother, it was clear on my first meeting with Liam that he was anxious about meeting me. For instance on first entering the room, Liam walked very quickly over to the window and looked out of it, avoiding all eye contact with me. This behaviour evoked anxiety on my part for a number of reasons. Firstly, I felt it was my responsibility to bring his levels of discomfort down and I was unsure whether I had the ability to do this. Secondly (and rather more selfishly), Liam was my last participant. I was by now operating within considerable time constraints and I did not want him to withdraw from the research.

Fortunately I was able to quickly apply a lesson I was learning through the course of the research, namely to place the participant at the centre of the research process as far as possible. As such, I simply asked Liam whether he wanted to continue standing up, or whether he wanted to sit down. I was surprised at how quickly he responded to this question, as he came and sat down very quickly. A good proportion of time during the first session - and beyond - was spent in this way, using simple choice-based closed questions during our interactions in order to ascertain what felt manageable to Liam with regard to our work together.

Using this kind of approach, I came to realise that the concept of choice itself was very important to Liam. I also realised that, once Liam felt he had a choice, it was possible for him to change his mind around certain positions he had previously taken. For instance during the first session, he was quite clear he did not want to discuss his school experiences as part of his life-story. However by the final session, he felt able to discuss school and to include a section on this in his life-story. It was noteworthy that Liam differed from previous participants in that he used significantly less verbal communication, tending to give either single words or short sentences as answers. However I realised through a process of trial and error that, by presenting questions in a closed rather than open format, with a choice of possible answers as prompts, the likelihood of Liam answering more fully was increased.

As my sessions with Liam progressed, particular attention was paid to Booth and Booth (1996:62) as highlighted in ***Chapter Three: Methodology***. These researchers consider narrative inquiry research methods with regard to participants who have fewer verbal language skills or who are unresponsive. In particular I was keen to experiment with some of the techniques they suggested. These included: Simplifying questions and giving suggested possible answers as described above; using "leading questions"; rephrasing questions in a hopefully less intimidating way; and where necessary, abandoning a topic and starting a new one.

With regard to working with participants with less verbal communication, Booth and Booth (1996) also highlight the danger on the one hand of rejecting particular lines of questioning too early, whilst on the other hand appearing overly inquisitorial. This was a balance I found particularly hard to strike with Liam. As was seen at the very outset of the first session, it was possible for Liam to change his mind following an initial refusal to discuss particular subjects, given the right questions and / or approach. However at times, I also had a strong sense that I had pushed him far enough with a certain subject. Signs of this included Liam's body language (shifting away from me, looking down at the table), as well as an increasing number responses such as "I don't know", or "I can't remember". As Liam appeared to have less verbal communication skills at his disposal than previous participants, it felt even more important for me to try to cue into these non-verbal indicators, in order that he still retained the sense of choice which was so important to him and, equally importantly, that his boundaries were respected.

That said and in contrast to the previous participants, Liam took much more control over the finished life-story product. In effect he dictated to me what he wanted written down, and he was very clear with me what he wanted to include and what he did not. As with previous participants who had also opted to leave certain sections out, this left me with a sense of disappointment that Liam's "whole story" was not captured. However in the case of Liam, I was particularly pleased that he felt able to take this control, and to retain ownership over the story by using me as scribe, acting - or not acting - on my suggestions as he saw fit. On further reflection, my own increasing confidence around the life-story technique itself may also have enabled

me to let go of some researcher control, in order that a more genuinely collaborative research partnership could take place.

Final Conclusions to the Life-Stories

Within this chapter, some of the richness of my experience of working with these young people has been conveyed. As described previously in ***Chapter Three: Methodology***, the finished life-stories are considered the "field texts" in this study. These life-stories and researcher reflections evolved into a "research text", after they were both analysed using a narrative analysis technique. This process revealed over-arching emergent themes, which will be discussed in ***Chapter Nine: Discussion of Themes***. Their relevance to the research questions of the study will also be explored.

CHAPTER NINE: DISCUSSION OF THEMES

Introduction

> I found that people were usually blinded by their own insecurities or egotism or selfishness. People seemed so ignorant in their self-assured black-and-white conception of 'normality'. Every so often however, someone would wonder whether others had something to learn from me in trying to understand my difference.
>
> (Williams 1992, p.146)

In light of the statement above from the published autobiography of a woman labelled with autistic spectrum, the preceding life-stories as well as the discussion to follow will improve our understanding of current participants' experiences of difference. This is of particular relevance to the primary research question, namely:

> *How do young people with the autistic spectrum label see their lives and experiences?*

With regard to this question and the narrative analysis processes described under ***Chapter Three: Methodology***, five narrative themes were revealed as common to several or all life-stories. These included relationships; special interests; self-knowledge and self-understanding; awareness of the autistic spectrum and finally experiences of school. All five themes are presented below under ***Emergent Themes*** and ***Researcher Reflections*** are also used in this analysis. Links are made with previous research with young people labelled as on the autistic spectrum. With reference to the second research question, relevant issues will subsequently be explored, by addressing the question...

> *How do these life experiences relate to theoretical models and disciplinary perspectives?*

Finally and on account of the relevance of psychological frameworks within the field of educational psychology, the final ***Chapter Ten*** will be devoted to exploring the implications of these life experiences for educational psychology practice.

Emergent Themes

Relationships

The importance of peer relationships featured in all the young people's stories: For instance, all three girls described a number of friends in their lives, whilst Liam regularly socialised with a boy from his school. As previously described, I also sensed that several participants were keen to interact with me. As such, although these relationship needs differed qualitatively with each participant, relationships were nevertheless built between all five young people and myself.

Despite this ability to construct relationships both with others and myself, a sense of social isolation and desire for increased contact with friends (and sometimes family) was evident particularly in some of the girls' stories. All three girls commented that they rarely saw friends outside school, and two of them expressed a wish for this to be the case. A desire for increased interpersonal relationships and friendships was also found in earlier studies with young people labelled as on the autistic spectrum (Cesaroni and Garber 1991; Molloy and Vasil 2004). Previous studies also found that diagnosed children suffered with feelings of loneliness and social isolation (Bauminger and Kasari 2000; Molloy and Vasil 2004; Humphrey and Lewis 2008).

With regard to the boys, a lack of extra-curricular peer contact was also evident. For instance in Fred's story, when at home, he wrote "I always watch telly". It is also noteworthy that within his story, Fred chose to report the visits of his sister's friends to their house, rather than an occasional visit by his own friend (briefly mentioned at the end of our work together). In contrast to Fred, Liam described more regular contact with a friend from school, however he too spent a lot of time watching television. In comparison with the two girls, it was less clear whether the boys actively desired increased social contact with friends after school.

Family relationships also featured within the stories to varying degrees, although the implications for participants appeared more complex. The content of Cassandra and Lizzie's stories, as well as of our wider conversations, suggested that the two girls

talked quite openly with their mothers about a range of topics including the autistic spectrum. Rachel's relationship with her mother in contrast centred on their shared love of horses, whilst Fred's story suggested a close relationship with his older brother rather than either parent. Both Cassandra and Rachel missed older siblings who had left home.

As is no doubt common in the majority of families with adolescents, issues of parental control were obvious in some of the young people's descriptions. However in these cases and perhaps not surprisingly, there was an additional element of control which appeared to relate to the participants' impairments. Cassandra's life-story and our associated conversations sometimes revealed a conflict between her desire to live her own life as a developing teenager, and her parents' views on this: As she described,

> When I learn to cope with my disability, my mum and dad say they will let me out on my own, when I learn to act better with it.
>
> (From Cassandra's life-story)

Despite the young people's obvious desire for relationships however, they were not easy to achieve. Cassandra's story revealed complications in her relationships, for instance with female friends at school, at times suggesting she felt bullied. She also described being physically tickled and taunted by a peer. Fred made reference to a similar experience with a difficult classmate in his story, whilst Rachel and Lizzie's stories both reveal perceived bullying experiences in (mainstream) Primary school.

Relationship difficulties and bullying experiences were also reported in previous studies of young people labelled with the autistic spectrum (Connor 2000; Molloy and Vasil 2004; Humphrey and Lewis 2008; Camarena and Sarigiani 2009; Tobias 2009). This will be discussed further below under ***Relevance of Developmental and Alternative Psychology Frameworks.***

Special Interests

Each participant had at least one special interest, which appeared to take a central position in their lives. As described earlier, it was sometimes a challenge to balance the participants' "individual worlds" with my own "world", including my research agenda.

It was however noteworthy that the essential individuality of each participant emerged through their respective and very diverse special interests. Moreover, it appeared that their interests also offered participants positive benefits, for instance with regard to building relationships with others. In the case of Rachel, her passion for horses gave her opportunities to spend time with her mother as well as with her friend "at the yard". For Lizzie, her understanding of the autistic spectrum allowed her to share relationships with school peers probably based on a sense of shared identity. Cassandra's interest in her developing sexuality offered her opportunities for "mother and daughter shops", whilst also providing a structure for "talking things through" with her auntie. For Liam, a shared interest with his friend ("The Chuckle Brothers") led to group social outings both with his friend as well as with their respective sets of parents.

In the case of my own experience with Fred, the implications of his special interest particularly for developing relationships was less clear. As described earlier, I had felt unable to build the kind of relationship I had wanted to with him. However it may have been that for Fred, the process of "being listened to on his own terms" may have been valuable in its own right, in a world where such opportunities were perhaps more scarce. For instance, although he told me he really enjoyed acting out the story of "Lilo and Stitch", in answer to my question about whether people in his life ever listened to him do this, he replied only "sometimes".

In some cases special interests also afforded positive opportunities for increased self-understanding. This was most obvious in the case of Lizzie, where her knowledge about the autistic spectrum served to create insight about both herself, about others such as her classmates as well as about her "normal" family relations. As she comments with regard to her understanding about the autistic spectrum:

> Learning this was helpful because it means I can know how much autism my friends have got, and also how much I have got. That also helps me understand my friends better and it helps me understand myself better.
>
> (From Lizzie's life-story)

Rachel's passion for horses helped her better understand her own place within the family, as she continued her maternal family's love of riding. In the case of Cassandra, her obvious preoccupation with her developing sexuality was clearly fraught with confusion and anxiety on the one hand, whilst also proving an exciting prospect on the other.

Self-knowledge and Self-Understanding

As described in Connor's (2000) study with young people labelled with autistic spectrum, through their stories and our wider discussions, nearly all current participants showed a capacity for self-understanding and self-knowledge, though this was to varying degrees: Lizzie's notable capacity for self-insight was revealed both in her story and during our conversations. Cassandra also described for instance how "I sometimes seek attention at school" and she felt very clear when a teacher had "invaded my space". A personal liking for solitude was clearly expressed by Rachel, again suggesting a degree of self-knowledge. During our final discussion, Liam revealed himself as able to reflect on his experience of our work together, saying it had been "tricky" on account of the "thinking" involved.

Moreover, all participants showed some understanding of the range of their emotional experiences as described within their stories and discussions, although this was more obvious with regard to the girls. For instance, Lizzie vividly described regular experiences of anxiety, which often centred around autistic spectrum related impairments such as her sensory experience of loud noises. Regular feelings of worry and anxiety were highlighted by Cassandra, for instance with regard to having a boyfriend and getting pregnant, whilst Rachel highlighted several occasions where she had felt "emotional" or "upset". Emotional references in the boys' stories were

less obvious, although Fred's story included a reference to his own and others' emotions.

Several participants described additional feelings of worry and anxiety specifically with regard to the longer-term future on leaving school, again more obvious in the case of the girls. For instance, Rachel expressed anxiety that, once she finished school, she may have to move away from her friends with her family, whilst Cassandra also expressed worry that she may not see her friends once she had left school.

It should finally be highlighted that all participants made references to positive emotional experiences. However comparatively more regular descriptions of challenging feelings also resonate with the narratives in Molloy and Vasil's (2004) study described earlier.

Awareness of the Autistic Spectrum

Several participants were aware of their autistic spectrum label. As also found in Molloy and Vasil's (2004) study, Lizzie was clear in her life-story that it helped to learn about the autistic spectrum. It was also clear from Cassandra's story that discussions had taken place with her around her diagnosis and in view of her enjoyment of "talking things through", it was likely that she found this helpful. Fred (as described by his mother) was aware he had "special needs" although unfortunately the opportunity was missed to explore this with him directly during our sessions. In effect, it was Rachel who appeared the most unclear about her autistic spectrum label. This was in keeping with her mother's views described earlier regarding Rachel's lack of awareness of her diagnosis, and the lack of direct discussion about it with her by her parents.

Lizzie stood out in her obvious desire to talk about her autistic spectrum impairments, for instance describing her sensory difficulties in some detail as well as difficulties around changes to her normal routines, both of which caused her considerable anxiety. Other impairments which she herself directly linked to her autistic spectrum label were revealed through her story. These included problems

understanding language as well as speaking "differently" herself, having a "different brain" to "normal" people, being "slower at learning", not knowing "when to stop" and not understanding social protocols such as when to go on stage during prize-giving. Lizzie too was clearly very aware of the differing degrees of autistic spectrum impairments of all her classmates. In Lizzie's view however, there were also some positive aspects of having autistic spectrum characteristics. These included being really good at drawing, enjoying younger children's cartoons as well as not knowing when things were real or not (e.g. dinosaurs) and "going on an adventure" to find out.

Cassandra's story also revealed an awareness of her autistic spectrum impairments, although to a lesser extent than Lizzie. For instance, Cassandra considered that as a direct result of her "Asperger's", she did not see the world like everyone else, had a tendency to be "rude" and was "not good with people who don't have disabilities". She also described "obsessions" with smells, textures and hugging people as well as difficulties when others speak too loud or "sit too close".

Cassandra and Lizzie both described common social experiences arising as a result of their autistic spectrum label, albeit not always wishing to include these in their stories. The range of descriptions included feeling different to others, not "fitting in", not being "understood" – and in Cassandra and Lizzie's case – sometimes also not being able to understand others. As described by Cassandra:

> I've got a disability called Asperger's Syndrome. I don't see the world like everybody else. (I do try and understand the way others see the world. I don't think others at home and school try and understand the way that I see the world). I'm a bit different to everybody else, because I don't really understand different people that well, I'm not very good at fitting in. It's not very fair really, I mean I do feel very left out especially outside of school. I don't play with very many people around here, and I would like to but I can't, so it's a bit unfair.
>
> (From Cassandra's life-story)

Likewise Lizzie reported feeling very different to the rest of her family. As she highlights:

> My sister doesn't understand me. I don't understand her because she's normal. My family don't have autism like me. I have a different brain to them. My family are all normal. They're all normal apart from my friend Ricky. He's the only one with Asperger's out of my whole family and friends outside of school. There's no one with autism in my family or the rest of my friends. They are all normal.
>
> (From Lizzie's life-story)

As described earlier, Fred's special interest "Lilo and Stitch" seemed to provide a relevant metaphor for the underlying experience of exclusion and sense of difference described by several of the participants. Such experiences of feeling different resonate with the perspectives of young people explored in several studies highlighted earlier (Cesaroni and Garber 1991; Molloy and Vasil 2004; Humphrey and Lewis 2008; Camarena and Sarigiani 2009; Tobias 2009).

Experiences of School

All apart from Fred reported that they preferred their (specialist) Secondary school to Primary school. With regard to primary school, four had gone to a mainstream setting whilst Liam had attended a specialist primary school. In her description of her mainstream Primary school, Lizzie commented that they "definitely did not understand me" - in her view, as evidenced by the amount of time spent working outside the classroom with a Teaching Assistant.

Rachel and Cassandra both commented on their sadness at separating from friends from Primary school (who had gone on to mainstream secondary school), and who they did not see any longer. Cassandra wished that she had gone with her old friends to Secondary school, as then "I would have had quite a lot of friends".

Reports about teachers both in Primary and Secondary school were mixed. For instance with regard to her current school, Cassandra was clearly disturbed by her teacher's recent handling of an incident which left her feeling "very shaky and very unhappy". It was likely that Lizzie particularly appreciated her (autistic spectrum

specialist) secondary school, in view of the volume of details she chose to include about this in her story. As portrayed in her story, Lizzie was obviously aware of the "normality" of her family, which was in contrast to her "different brain". As also seen in her story, Lizzie had a clear interest in the autistic spectrum itself. In view of these issues, school was probably providing Lizzie with a sense of relief at being with people who shared the same autistic spectrum - related experiences as her.

This sense of relief experienced by being with others who share the autistic spectrum label was also described in Molloy and Vasil's (2004) study, whereby young people reported benefits of attending "Asperger" support groups for similar reasons.

Links with Theoretical Models and Disciplinary Perspectives

As detailed earlier in ***Chapter Two: Literature Review***, there are a number of perspectives with which the autistic spectrum can be viewed, the most common being medical and traditional developmental psychology frameworks. However, social perspectives were also revealed as highly relevant, for instance a social model of disability or alternatively a social constructivist perspective as applied to the autistic spectrum field. All such perspectives will now be reconsidered in the light of themes to emerge from the life-stories and associated researcher reflections.

Links between the Life-Stories and a Social Model

Social barriers and relationships

It could be argued that the participants experienced a fundamental sense of powerlessness over their own lives, on account of the disabling social barriers they faced. For instance, they were clearly reliant on their parents to organise extra-curricular social contact with school friends and other peers. A lack of inclusion within their local communities was also revealed in the current stories, and as such it was arguably even more important that participants were encouraged to foster existing friendships. Although geographical distance was cited by several participants as the reason their parents did not arrange for them to see friends after school, it is also feasible that parents did not fully appreciate their children's need for increased social peer contact. If this was the case, it is possible they were adhering to the stereotypical view of individuals labelled with autistic spectrum, namely that they do not need relationships nor value social above individual worlds (Bagatell 2007; White and Roberson-Nay 2009).

This tendency to form negative attitudes based on their label had also at times been reflected in my own manner towards participants: For instance, earlier on in the research my tone had been somewhat patronising, as though I was speaking to much younger children. Situations such as these highlight a process whereby incorrect attributes are conferred by others onto labelled individuals. In this way unhelpful

social constructions around labels such as the autistic spectrum and associated impairments are created, leading to a view that.....

> ...disability involves the social oppression of people whose impairments mark them out, or are *discursively constructed* as marking them out, as 'different.'
>
> (Thomas 2007, p.49, my italics)

Social barriers were additionally faced by participants owing to a lack of opportunities for involvement in their local community. As a result, the participants were highly dependent on school for peer relationships: In the case of Lizzie, it is arguably possible to infer from her life-story that school was in some respects her "life-line" – a place where she felt understood by others who shared her impairment experiences. This resonates with the views of teenagers from Molloy and Vasil's (2004) study as well as with the narrative of Ben (Bagatell 2007), for whom attending autistic spectrum support and social groups increased feelings of belonging. However, as subsequently seen in Ben's narrative (Bagatell 2007), such groups are not ultimately a substitute for other social relationships. As Ben describes,

> 'I am sick of social skills groups....Why can't someone go to the bar with me or chess club? That's what I need.' Perhaps by shifting attention from deficits to social participation, individuals with autism, like Ben, may be better prepared to engage in the process of identity construction, leading to a full and meaningful life.
>
> (Bagatell 2007, p.425)

With the exception of Rachel, nearly all friendships described by the participants were with peers from their (specialist) school. Opportunities to build relationships with adolescents without the autistic spectrum label did not appear to be readily available, no doubt further reinforcing participants' feelings of difference in comparison with their peer group. This was partly a function of their life experiences: Having been excluded from all other avenues, then the only people they would meet would be those with the same label. Rachel was the only young person who described an active friendship with a peer who was not diagnosed with

autistic spectrum. It is possible that the opportunity for Rachel to continue her family's horse-riding tradition was equally valuable in its potential for contact with a world "outside of the autistic spectrum".

A further undercurrent to the stories includes the reactions of others to participants, and most notably a lack of social understanding of difference. For instance, Cassandra's attempts to explain her differences to peers in her local neighbourhood were singularly unsuccessful. My own reactions to difference had also been clearly portrayed, whereby my anxiety and fear at the outset of the research slowly evolved into a concern with trying to place the participant at the heart of the research process. As described by Oliver (1990) with reference to a social model view of disability, such anxiety on the part of others is a common social barrier faced by those who are perceived to be different, which becomes a feature of systemic social prejudice towards them. My own increasing confidence was achieved only through the process of building individual relationships over time, rather than viewing the young people as a homogeneous group sharing the same label and hence the same ("insurmountable") difficulties.

Finally, social barriers in the lives of participants were evident in that key decisions around when they could engage in "typical" teenage activities were clearly to be taken by parents. There was little sense that the young people were currently treated as equal partners in the decision-making processes about their lives, and particularly social lives and relationships, to a significant degree.

Social barriers and identity

With regard to an "autistic spectrum identity", participants were dependent on the amount of information their parents (and school) chose to give them. Clearly some were more informed than others, and some more willing to talk about the subject than others. However one could not help but wonder about the effects on Rachel of not having discussed her label with her family nor apparently at school, thus contributing to a lack of clear understanding of her own individual differences. Such a lack of information could ultimately obstruct Rachel's understanding of herself and her own life. If one assumes a "second-wave" interpretation of the social model

which, in addition to a focus on social barriers also emphasises the lived experience of impairment (e.g. Hughes and Paterson 1997), it was clear that the latter was not currently a feature for discussion in the life of Rachel and her family.

When reading Lizzie's story on the other hand it could be argued that at times she over-identified with her autistic spectrum label, as also seen in the case of one of the participants in Molloy and Vasil's (2004) study. Nevertheless, identification with the autistic spectrum label may well have been enabling Lizzie to experience a shared identity with her similarly labelled peers based on a perceived sense of shared mutual understanding. It was likely that this shared identity was all the more important to Lizzie on account of feeling so different to members of her own "normal" family. The need for a shared autistic spectrum identity was also seen in Ben (Bagatell 2007), who experienced a huge sense of relief on entering the "Aspie" world. Experiences of shared identity such as these form the foundations for the growing self-advocacy movement within the autistic spectrum field (Rose 2008).

This is also of relevance to Oliver's (1990) social model view of disability, whereby the cultural portrayal of images through the media, films and books has ensured that disabled people have historically been portrayed as either "pathetic victims of some appalling tragedy or superheroes struggling to overcome a tremendous burden" (Oliver 1990:61). As such, identities are externally imposed onto disabled people by their cultural environment (Oliver 1990). In the case of the autistic spectrum, it could be argued that labelled individuals are portrayed within the media as "mad," or "loners", although also sometimes as "triumphant" as in the film "The Rain Man". Importantly however, all such identities are externally prescribed and thus lend themselves to being challenged and opposed by the individuals involved (Oliver 1990). Increasingly, the self-advocacy autistic spectrum movement as well as the growing numbers of autobiographical publications combine to challenge popular social portrayals of the autistic spectrum. As such, an alternative collective identity to popular cultural portrayals is claimed, in a similar way to processes within the deaf community (Rose 2008).

However it is important to highlight that, with regard to patterns of "group identity", these related as much to gender and age as well as to a shared autistic spectrum label.

For instance, the girls' stories were clearly far longer than those of the boys, reflecting also that the girls were more willing to talk to me in depth than the boys (although as described earlier, the boys differed greatly from each other in their approach to the life-story work and the way they chose to interact with me). Gender differences were also present in the apparently stronger ability of the girls to reflect both on themselves as well as their own emotions. A similar group identity around their age was also evident. For instance and through their life-stories, all participants revealed themselves as interested in areas that commonly attract the attention of teenagers, e.g. computer games, TV, puberty and horse riding. There is no doubt too that my own age and gender status mediated my relationships with the participants. Had I been male for instance, it is likely that a different "group pattern" with regard to gender would have emerged. My status as a person without the autistic spectrum label no doubt also influenced the nature of our interactions. As Oliver (1990) describes in this regard, cultural identities externally imposed on disabled people all too often do not account for other aspects of their identities, hence compounding already existing socially disabling barriers for people with impairments on account of other equally important aspects such as their gender, race, age, etc. (Oliver 1990).

Social barriers within the research process

Even within the research itself, social barriers were created that at times obstructed the course of the research. For instance, negotiating confidential access to the young people had posed significant challenges even once the sample had been identified and agreed. Parents had needed ongoing reminders of the need for a private room, and of the fact that their child's story was confidential. Similarly when undertaking the life-stories at school, regular interruptions took place whilst sessions were underway, again despite regular requests for privacy. Given these situations and despite repeated assurances around anonymity and confidentiality, it was not surprising that several participants chose not to include elements of our wider discussions in their stories. Hence and to varying degrees, the stories were "sanitised", most likely in order to make them acceptable to parents to whom all participants decided to show their finished stories.

Yet, ironically it was through this process of final editing that participants exercised their power at least within the research process, as they exercised agency over what to include and what to leave out. It was likely in some cases that participants omitted certain sections in order to protect the feelings of their parents and other family members or school professionals. In this regard, they revealed themselves as choice-making individuals, active agents, sensitive to the needs and feelings of others and able to adapt themselves accordingly. As such, although a lack of power in their lives was undeniable, it would nevertheless be wrong to construct these young people solely as "powerless victims". Such a view is in direct contrast to a social tendency to generally perceive disabled individuals only as victims with little sense of their own power (Oliver 1990; Atkin and Hussain 2003).

It could be argued that, through the final editing of their life-story, participants were able - at least partly - to access their own voice, in a world dominated by the voices of more powerful adults. As described by Booth and Booth (1996), through narrative inquiry research methods such as the life-story method, barriers faced by marginalised groups are lifted with regard to their inclusion in academic research and potential for being heard:

> The 'excluded voice thesis' postulates that narrative methods provide access to the perspectives and experience of oppressed groups who lack the power to make their voices heard through traditional modes of academic discourse.
>
> (Booth and Booth 1996, p.55)

The links between the current life-stories and a social constructivist perspective on the autistic spectrum will now be explored.

Links Between the Life-Stories and Social Constructivism

Social constructivism and "individual worlds"

In some cases participants' special interests appeared to have the effect of creating another world for the participant as we worked together. As previously described, it felt at times as though my world (and the research agenda) was competing against the individual world of each participant. This was particularly true in the case of Fred, where his world seemed to seal him off from me. There are a number of possible reasons why this may have happened: For instance, Fred may have felt anxious around me and may not have wanted to do anything that he perceived as beyond his capability. By disappearing into his own world Fred retained a lot of control over how we spent our time, in contrast perhaps to his encounters with the "outside world" where he may have experienced a good degree of powerlessness over social interactions. It is noteworthy that, when working with Fred, I sometimes felt dominated and marginalized and again, perhaps this was a reflection of his own experience of the "outside world".

An alternative explanation of Fred's apparent preference for his individual world may have been that he actually felt quite happy there, hence experiencing little need to leave it. In this sense, I was the one with the problem rather than him, as it was I who was finding his choices uncomfortable. Although it is impossible to directly compare the experiences of Fred and Donna Williams for reasons described earlier, this tension between an individual world and the "outside world" resonates with the words of Donna Williams in her published autobiography ....

> These 'helpful' people were trying to help me 'overcome my ignorance' yet they never tried to understand the way I see the world. It seemed so simple to them. There were rules. The rules were right. I obviously needed their help to learn them.
>
> (Williams 1992, p.78)

When adopting a constructivist perspective, it is argued that there are many ways of viewing reality and experiencing "the world". It is a medical model approach which privileges a particular and apparently "normal" experience over others. If reality were regarded as multi-faceted and diverse, then the choices made by Fred during

our work together would be viewed as an expression of his different construction of "the world" compared to my own - different but not necessarily representative of individual pathology. Moreover, the choices I made within our work together may also have hindered our respective abilities to share worlds based on a shared understanding of reality, reflective also of the social nature of reality construction. For instance if I had watched the film of "Lilo and Stitch" with him and used that as a platform for the interviews, this may have paved the way for more two-way communication between us. A final alternative explanation for Fred's retreat into his own individual world may have been reflected by a possible reaction by him, to being made to feel different within a society that is obsessed with being "normal".

Several other participants also created individual worlds, most notably through their special interests: However in contrast to Fred, Cassandra regularly and repeatedly tried to make a bridge between her world and mine, through her ongoing questioning around sexual and adolescent development. Such differences in the way participants managed their negotiations between their own world and the outer social world again reflected their individual differences and fundamental uniqueness.

"Normality" and difference

Several participants expressed a sense of feeling different to others. For instance Lizzie expressed her understanding of the concept of "normality" within her life-story, a concept with which she herself could not identify. Cassandra's descriptions of being different and "not fitting in" also implied a similar notion of "normality" from which she too felt distanced. Whilst again avoiding direct comparison between the preliminary readings and the life-stories of the main study, such experiences of feeling different when living within a dominant social discourse of "normality" were also neverthless described within the published autobiographies (See ***Appendix 10*** for additional details about these descriptions). For instance, Holliday Willey (1999) speaks of her desire not for a cure of her autistic spectrum impairments, but rather of a remedy for society's fixation on "normality". Interrogation of such a cultural discourse of "normality" is also a feature of a social constructivist perspective: In this regard and in her analysis of autobiographies published by adults labelled with autistic spectrum, Smith (1996) highlights Grandin and Scariano's (1986)

portrayal of the irony of such a normal / difference dichotomy when the very nature of the autistic spectrum itself has been so contested over the years:

> In this way, she captures the ongoing construction and reframing of autism and emphasises its unfixedness against the fixedness of diagnostic labelling and the fixedness of theories promoted by certain experts.
>
> (Smith 1996, p.241)

Through writing her autobiography, the opportunity is created for Grandin to reframe her own unhelpful constructions both of herself and of the autistic spectrum (Smith 1996). As such, she now no longer considers herself as "mad" rather as "autistic" (Smith 1996). Through the process of writing and publishing autobiographies such as this, a counter discourse to that of deviance and pathology is created whereby behaviours make perfect sense when seen in the light of autistic spectrum impairment difficulties (Davidson 2007). Here, through the process of creating their autobiographies, those with the autistic spectrum label and "through their narrative efforts....resist identities attached to their behaviours and redefine themselves" (Smith 1996:243).

It is likely that similar self-reframing processes were at play for the current participants as they jointly created, revised and edited their life-stories. Moreover, through the process of reading published autobiographies and life-stories such as those in the current study, the social constructions of their readers with regard to the autistic spectrum are also challenged.

Having reconsidered some social perspectives in the light of emergent themes from the current study, a medical model view will now be further explored. This will be followed by an examination of the links between the current life-stories and a traditional developmental psychology framework, whilst alternative psychological frameworks will also be discussed.

The Life-Stories and a Medical Model

Ironically social constructions of selves as engaging in meaningful behaviour in the context of autistic spectrum impairments, could not have been achieved without reference to a medical model which categorises such impairments. The value gained from a medical perspective is also highlighted within the narrative inquiry study of Ben's identity development (Bagatell 2007) described earlier whereby.

> Hearing a doctor talk about the neurological aspects of autism helped Ben to construct a new life narrative, to reframe his experiences and behaviours.
>
> (Bagatell 2007, p.419, my italics)

This resonates with Lizzie's views, where she found increased knowledge and understanding around the autistic spectrum helpful, whilst both Williams (1992) and Holliday Willey (1999) expressed relief on taking on the autistic spectrum medical label in adulthood. When living in a world where medical diagnoses are constructed as important, it would seem that labels such as the autistic spectrum are reassuring in terms of explaining difference. Moreover, it was clear particularly in the case of Lizzie that identification with her medical label had several positive effects: Firstly, it enabled her to develop into a "success story" in the eyes of her teachers, whereby her "achievements" were celebrated by them as she gradually and partly overcame her autistic spectrum- related impairments, akin to the final "triumphant" theme seen in the "Rain Man" film. Also and as previously discussed, identification with her medical label probably enabled Lizzie to experience a shared identity with her similarly labelled peers, with all the benefits that this brought.

Such positive elements arising from medical labelling processes reveal the complexity of the issues at hand, such that it becomes important not to over-problematise medical practices of assessment and diagnosis. As highlighted earlier by Gillman (2004), labelling and diagnosis practices are not unhelpful per se. In contrast, it is the rigidity and fixedness of the conclusions drawn from such labels that are counter-productive, leading to a wider tendency to group people into a category that precludes recognition of the spectrum of individual difference seen in

people without the label. Yet, as seen within the current life-stories and wider conversations of the present study, there were important individual differences between participants. These were evidenced for instance in their wide variety of special interests as well as in the contrasts between their various personalities. Their senses of humour were dissimilar, their individual responses about relationships with families and friends were very varied and there were notable differences in the subjects participants wanted to discuss and avoid. My experience of working with each participant revealed that the differences between them often outweighed their similarities as a result of a shared autistic spectrum label. This resonates with Davidson's (2007) analysis of autobiographical publications by adults with the autistic spectrum label, where significant individual differences were also found between each author. It is these aspects of individual difference within autistic spectrum diagnoses that is missed by a purist medical model view.

A related danger of a fixed adherence to diagnoses is that a person's medical label becomes their identity, at least in the eyes of others and sometimes in their own as well (Gillman et al. 2000). As already described, I had become part of this process upon allowing participants' diagnoses to screen out other factors relating to their identities, for instance being a teenager.

Relevance of Developmental and Alternative Psychology Frameworks

A traditional developmental psychology view

There were several contradictions between findings from the current study and those reported in the epistemologically positivist developmental psychology field. For instance, the current life-stories revealed some positive benefits arising from participants' special interests, including opportunities for shared relationships as well as increased self-understanding. This is in contrast to traditional developmental psychology literature where special interests are described using the language of pathology, deficit and disorder, symptomatic of a disordered cognitive style (as seen for instance in Bailey et al. 1996; Trevarthen 1996; Green et al. 2000). The evident capacity for self-understanding of current participants, and their understanding of others, is also in contrast to a traditional developmental psychology model of the

autistic spectrum whereby children labelled as on the autistic spectrum are deemed to lack "theory of mind", precluding an understanding of their own mental states, as well as those of others (Baron-Cohen and Bolton 1993). Previously reviewed psychological research also highlights that diagnosed children struggle to understand and express their own emotions.

That said, there were clear links between Lizzie and (to some extent) Cassandra's descriptions of their lived experience of autistic spectrum impairments and the developmental psychology literature previously reported. These impairments spanned across all three areas previously reviewed, including the social arena (maintaining friendships, managing social situations), experiences of emotions (difficulties controlling oneself) as well as language (understanding and using language) and cognition (difficulties with learning; problems with changes to the routine; sensory impairments). Whilst these impairments were usually described in negative terms, Lizzie's view that not all autistic spectrum characteristics are problematic is of particular relevance to a traditional developmental psychology discourse of deficit and disorder. For instance, Lizzie described her enjoyment of younger children's TV programmes (also appreciated by Liam) as a positive advantage – "the fun part of autism"- compared to her friend without an autistic spectrum label who did not enjoy them. It is viewpoints such as these on individual lived experience that is missed in much traditional autistic spectrum psychology research.

The autistic spectrum social skills difficulties reported earlier in the psychological research (e.g. Frith 1989; Bailey et al. 1996; Trevarthen 1996) were also evident in the current stories, for instance in Cassandra's descriptions of arguments with peers. However, what is unclear both from current and previous studies is the extent to which social peer attitudes to difference are responsible for such difficulties, as opposed to the effects of autistic spectrum social impairments themselves. For instance in the case of Cassandra, there was sometimes confusion on her part (and hence on mine as well) over whether she was being directly bullied by others, or whether her own social impairments were themselves standing in the way of her relationship-building. It is likely that, in accordance with a traditional developmental psychology child-deficit view, individual social skills difficulties are over-

emphasised in situations such as these, whilst the child's environment in the form of unhelpful social attitudes around difference is ignored. As Molloy and Vasil (2004) describe with regard to "Asperger's Syndrome",

> Why is it we wonder, given that AS, as a medical syndrome, is characterized by a child exhibiting poor social skills and the inability to make friends, that when that child is placed in a less hostile environment with other children there is frequently a marked increase in social interaction, and friendships often develop? The ability to form these friendships in safer environments may indicate that stigmatisation, or at least the child's sense that they are different from others, might be a factor in preferring solitary play, although other issues, such as sensory overload, may be important as well.
>
> (Molloy and Vasil 2004, p.124-125)

It should be noted that Cassandra's situation highlights the danger of focussing either solely on individual impairment or on the environment, to the complete exclusion of the other: In assuming that the cause of problematic relationships are autistic spectrum-related social difficulties, genuine instances of bullying may be missed, thus setting up further barriers for individuals such as Cassandra with regard to achieving fulfilling friendships. Conversely, through a narrow focus on the bullying behaviours of others, opportunities may be missed to help individuals develop their own social and relationship-building skills. It is possible that some of the participants' mixed responses towards school (both mainstream and specialist) may have been explained by a lack of such differentiation within these environments between the effects of environment on the one hand, and the effects of individual impairments on the other.

Possibilities offered by alternative psychology frameworks

There is a dearth of psychological literature whereby alternative less deficit-driven psychological frameworks are applied to the autistic spectrum. These might include applications from a social psychology systems view (e.g. Bronfenbrenner 1979), whereby the child is considered in the context of the environment. Here the impact of varying systems such as family, school, community and wider cultural and political systems are also considered to affect the experiences and behaviours of

children. Viewed from this social ecological perspective, the chosen "narrative" (in the sense of social discourse) of the school or family around the autistic spectrum would affect the child's experiences of living with this label.

Alternatively, a humanistic psychology model (e.g. Rogers 1951; Maslow 1970) could also be applied to the autistic spectrum field. For instance the need for all people to experience a sense of belonging and a sense of worth is highly relevant when considering the current participants' feelings of exclusion and difference, as well as the social barriers they faced. There is moreover a gap in the literature with regard to the views and experiences of young people labelled with the autistic spectrum themselves. In line with a social constructivist epistemological stance, it could be argued that applications of Personal Construct psychology (e.g. Kelly 1963), would be useful in exploring the world-views of children in order that a better understanding of their individual lived experiences can be gained.

In line with Lizzie's view on the "fun part of autism" and the notion that special interests are not necessarily pathological - and in contrast to a developmental psychology focus on deficit and disorder - the field of Positive psychology (Seligman and Csikszentmihalyi 2000) provides a helpful alternative with regard to focussing on assets rather than deficits within the autistic spectrum. Finally the life-story research method (e.g. Lieblich et al. 1998; Crossley 2007) as applied within the current study holds particular promise for autistic spectrum research. Whilst the study has several limitations (to be discussed below), it has furthered understanding of the individual experiences of the young people involved, with the subsequent aim of facilitating social change through EP practice.

Emergent Themes: Conclusions

Social barriers within participants' local and wider environmental contexts were revealed as very pertinent to the participants' lives. However, it should not be denied that participants also lived with autistic spectrum - related impairments to varying degrees. Whilst medical and traditional developmental psychology models do address such issues of impairment, they do not however allow for portrayals of unique lived experience as captured in the current study. Moreover within such models, impairment is constructed as representative of deficit and disorder, whilst considerations of environmental and social barriers as experienced by diagnosed young people are absent.

Social perspectives and alternative psychological frameworks with regard to the autistic spectrum were highly relevant to the current study. With regard to the social barriers faced by participants, a pure social model (Oliver 1990) was shown to be significant. However it is also argued that adherence to a pure social model view of disability can "side-line" impairment (Hughes and Paterson 1997). This view paves the way for a "second wave" of social model theory (Hughes and Paterson 1997) whereby social barriers faced by participants are interrogated, whilst awareness is raised of the unique nature of their lived experiences of impairment. Furthermore, experiences of exclusion and difference were clearly portrayed in both Cassandra's and Lizzie's life-stories, whilst nevertheless living in a society where the dominant discourse is one of "normality". As such a social constructivist perspective is also highly relevant, in order that popular but unhelpful attitudes about the autistic spectrum can be examined and ultimately reframed. Finally and in place of traditional developmental psychology models, alternative social, humanistic and positive psychology frameworks are considered as important. These offer the possibility of redressing the balance within the traditional developmental psychology field. The latter is currently restricted by an exclusion of environmental considerations and by a narrow emphasis on deficit notions of impairment. The significance of such alternative frameworks for the practice of EPs will be discussed in the final chapter, after consideration below of the limitations of the present study.

Limitations of the Present Study

As detailed earlier in ***Chapter Three: Methodology***, narrative psychology and life-story research methods have many strengths. For instance, they improve understanding of unique lived individual experience, whilst also offering the opportunity for therapeutic benefits from the research experience.

Limitations of Narrative Inquiry Approaches

Although rooted within the branch of narrative psychology, the current study was also linked to the broader narrative inquiry field, an approach which is characterised as spanning a broad variety of fields and disciplines (Daiute and Lightfoot 2004; cited in Creswell 2007). As such there is huge diversity in ways in which narrative inquiry can be used. For instance it is employed both as an approach to data-collection as well as with regard to data analysis (Creswell 2007). As highlighted by Reissman (Reissman 1993:16-17), "There is no binding theory of narrative but instead great conceptual diversity". As a consequence of this, there are few prescribed ways in which a narrative inquiry can be carried out, few "how-to manuals" to consult, thus rendering it particularly complex and challenging to use (Lieblich et al. 1998; Creswell 2007). This was certainly reflected in the experience of carrying out the present study, which at times felt a little akin to a journey of discovery.

Narrative inquiry has also been criticised for its lack of potential for representativeness and generalisability to a wider population (Crossley 2007). It is usually based on small sample numbers as in the case of the present study. Experimental research concepts of reliability and validity also cannot be applied to a narrative inquiry study (Reissman 1993). As such, narratives such as the life-stories in the current study also are not representative of "the truth" (Atkinson 1998), and neither are their analytical interpretations. As described by Reissman (1993) with regard to narrative inquiry studies...

> All forms of representation of experience are limited portraits. Simply stated, we are interpreting and creating texts at every juncture, letting symbols stand for or take the place of the primary experience, to which we have no direct access. Meaning is ambiguous because it arises out of a process of interaction

> between people: self, teller, listener and recorder, analyst, and reader. Although the goal may be tell the whole truth, our narrative about others' narratives are our worldly creations.....Meaning is fluid and contextual, not fixed and universal. All we have is talk and texts that represent reality partially, selectively and imperfectly.
>
> (Reissman 1993, p.15)

Upon accepting that life-stories cannot represent "truth", some would go so far as to say they can therefore be considered as no more than "fiction" (e.g. Denzin 1989). As such, it is not difficult to see how the field of narrative inquiry is sometimes considered as an art form, rather than a rigorous scientific method (Crossley 2007), easily leading to criticisms of heightened subjectivity, individualisation and personalisation (Atkinson 1998; Clandinin and Connelly 2000).

A further difficulty experienced during the analysis of the life-stories was that there is no one "correct" interpretation of them (Atkinson 1998), rather there are always multiple possibilities for narrative analysis (Atkinson 1998; Chase 2005). This further reinforces the subjective nature of the analytic and interpretive process. Moreover, and in contrast to the aims of experimental research, a further criticism levelled at the narrative inquiry field is the notion accepted by narrative inquiry researchers that they influence the data. This is portrayed for example through the quality of the researcher / participant relationship, which often has a significant impact on what is relayed in the subsequent story (Atkinson 1998). In this regard it could be argued that, compared to the boys, the girls' relative willingness to talk to me was a direct reflection of our qualitatively stronger relationship. This resulted in girls' stories that were much richer in terms of content, depth and detail.

It is also accepted in studies such as this that the researcher will also significantly influence the process of data analysis. This is evidenced by the treatment of current researcher reflections as data, and by the acknowledgement that the chosen ways of both analysing and interpreting data are strongly influenced by the researcher's preferred theoretical models and stances (Goodley, Lawthon, Clough and Moore 2004). Within the current study, a personal adherence to social perspectives on the autistic spectrum, and to social and humanistic psychology frameworks, has no doubt

influenced conclusions drawn from the data. A final criticism of a study such as this might be levelled at the existence itself of analytic interpretation of the stories, which arguably takes final ownership of the stories away from the participants themselves (Goodley et al. 2004).

Whilst not denying the need to take such criticisms very seriously, counter-arguments to these criticisms are also relevant to the present study. For instance and with regard to life-story work, Goodley et al (2004) introduces considerations of "authenticity" in place of validity with regard to life-story study. He describes this as an epistemological stance which is…

> …engaged with the authentic meanings of a story and its narrator rather than devising measures that measure what they purport to measure..
>
> (Goodley et al. 2004, p.98)

As far as the issue of "truth" of life-stories is concerned, Goodley et al. (2004:107) consider that it is more important that stories such as those in the present study promote "positive social change". Lieblich et al. (1998) also argue that, rather than focussing on the "truth" or validity of a narrative, a process of "consensual validation" should take place, whereby ongoing dialogues take place with other researchers to share ones' interpretations and subject them to critique. The concept of "trustworthiness" has also been proposed (Reissman 1993; Atkinson 1998). According to Reissman (1993:64-68) this can be gauged by four principles: "Persuasiveness" (an examination of whether the analysis is grounded in the data as well as in theory); "correspondence" (ensuring the stories and interpretations are checked with participants involved); "coherence" (including whether important themes recur through the narratives) and finally "pragmatic use" (which concerns how relevant the study is for future research directions). The current study is considered to meet three out of four criteria for "trustworthiness." However, with regard to the concept of "correspondence," although the life-stories were finalised by the participants themselves, subsequent researcher interpretations were not checked by them. This could be considered as a significant limitation.

Atkinson (1998) considers that the "trustworthiness" of life-stories can be further assessed by allowing a close relative to check if they are factually correct, in essence as a form of data triangulation. In actuality, the current study was carefully designed to screen out this possibility, in order that the voices of the young people could be heard in their own right. However, clearly the disadvantage of such a decision was the loss of opportunity for data triangulation such as that proposed.

Finally, Goodley (1996) reinforces the importance of researcher reflexivity and transparency around inferences made from a narrative analysis of life-stories. The centrality of researcher reflections within the current study have been made explicit in this regard.

Limitations of the Current Study and Implications for Future Research

A particularly challenging issue encountered as the study progressed included decisions on the part of several of the participants, and most notably Lizzie, to omit important elements of our wider conversations from the final life-story. However, as described by Atkinson (1998), within the process of co-creating life-stories the participant should have ultimate authorial control over their story, and this must take precedence over any research concerns for rich data. As such, only the life-stories as finally revised and edited by participants are treated as research data, with the consequence that some valuable participant insights and experiences from our wider discussions are omitted.

Further constraints specifically relevant to the current study included that narrative analysis of the stories relied very much on their content. It could be argued that the study would have benefited from supplementary "participant observations" as a technique for both triangulating and adding to the stories. This approach may have furnished useful further information relating to autistic spectrum impairments, a topic which using the current data collection / analysis methods, only Lizzie really discussed in depth. As such it is considered that combining a participant observation approach with the life-story research method would prove a fruitful direction for future research.

Also with regard to choices for data analysis, a thematic narrative analysis was employed which again focussed very much on content (Lieblich et al. 1998), rather than for instance on the form of the stories such as their tone (e.g. Crossley 2007), type of plot (Lieblich et al. 1998) and use of language and vocabulary. A triangulatory analysis undertaken from these latter angles may have provided useful insights into how children with the autistic spectrum label construct stories about themselves and in particular, use language. As such future research should include a wider array of narrative analysis tools in order that the richness of the data can be fully explored.

Also with regard to data analysis, although several participants used the digital camera to take photos or make a video, these were not treated as research data within the current study, rather simply as a stimulus for the oral life-story interviews. As such it could be argued a valuable opportunity was lost to triangulate data emerging from the stories themselves. There is therefore a need for future research to make full use of technological visual aids and equipment, and to treat visual data with the same respect as the written word during data analysis processes. Such approaches would be particularly relevant when working with young people labelled as on the autistic spectrum but with less language than those in the present study. It is also important to consider creative interpretations of the life-story method and adapt these to individual participants. Consideration should be given for instance to using alternative research mediums such as fiction, as a framework for eliciting young people's experiences, if participants struggle to respond to traditional methods, as in the case of Fred.

Finally the study was constrained by time. There was a sense that richer life-stories may have been created particularly in the case of the boys, had more time been available to build stronger relationships with them from the outset.

Conclusion

The current chapter has examined the themes and issues arising from the life-stories, whilst relevant links to theory and disciplinary perspectives have been made explicit. Some key limitations have also been presented alongside suggestions for future research.

The study will now conclude with a consideration of the relevance of psychological models as they apply to current findings, together with an exploration of their implications for the practice of EPs.

CHAPTER TEN: CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

Introduction

Following narrative data analysis of the life-stories within the current study, certain key themes emerged from the stories. These related to a desire for increased social relationships particularly outside school, as well as the existence of difficulties and perceived bullying within participants' present and past relationships. In contrast to a traditional developmental psychology view, participants' special interests offered some positive benefits for their lives, whilst the young people also showed a capacity for self-understanding and self-knowledge to varying degrees. Again in contrast to some of the psychological literature and particularly in the case of the girls, participants showed an ability to identify and discuss their emotional experiences, and in particular described more challenging feelings such as worry and anxiety.

Several participants felt it was useful to both have information about their autistic spectrum diagnosis as well as to discuss it with others. In the case of Lizzie, it is possible that she over-identified with the autistic spectrum label at times, although being at school was particularly valuable as it enabled her to experience a shared identity with others. Nearly all friendships described by the participants were with peers from their specialist provision, who were also labelled with the autistic spectrum. With regard to the effects of their diagnosis, some participants placed a strong focus on social barriers such as not belonging and not feeling understood. Some also referred to their autistic spectrum related impairments. Descriptions of school experiences were mixed, although nearly all preferred their secondary (specialist) school to primary school.

There were important individual differences between participants and their stories, which were greater than autistic spectrum-related similarities. In terms of group similarities, these were evident with regard to gender and age, as well as effects of the shared medical label. Although they showed active agency within the research process, participants faced a range of social barriers within their own lives. These

included lack of opportunities for involvement in their local communities and lack of facilitation by parents of peer contact after school. On a wider level, disabling attitudes were revealed on the part of others including the researcher, whilst the effects of living in a society dominated by the discourse of "normality" also emerged.

The implications of these findings for EP practice will now be discussed.

Implications for Academic and Professional Educational Psychology

Direct Insights from Emergent Themes

Direct implications for EPs involve incorporating the above insights gained from participants' life experiences into one's own professional practice, as well as "cascading" those insights to other EPs, teachers, other professionals and parents. Such realisations include: challenging popular stereotypical assumptions that autistic spectrum diagnosed young people are not interested in nor value social relationships; questioning suppositions that they are unaware of their own and others emotions, or lack the capacity for self-reflection; interrogating the view that their special interests are necessarily pathological; and reframing popular notions that such young people are unable to exert active agency on their own behalf. These stereotypical attitudes tend to arise from a fixed adherence to dominant medical and traditional psychology perspectives on the autistic spectrum. In contrast, EPs need to recognise - and encourage other professionals and involved adults to recognise - that young people are first and foremost unique individuals with strong individual differences, regardless of their medical diagnosis.

Nevertheless, the issue of medical labelling and diagnosis cannot be ignored as young people live in a society where medical labels exist. Given this fact, and as suggested by the findings from the current study, information about their autistic spectrum label and its implications – both social and individual - is likely to be of benefit to young people. EPs therefore need to highlight the importance of open and honest discussion of their autistic spectrum label with diagnosed young people, whilst families clearly need to be jointly engaged in this process. Involved adults, including EPs, need to be aware that diagnoses can provide relief to individuals and families by taking away uncertainty (Gillman et al. 2000). They are not detrimental as a standalone concept (Keil, Miller and Cobb 2006), although it is the social constructions of others around those labels that are sometimes unhelpful. EPs also need to be conscious of the fact that according to current educational systems, diagnoses often open the door to particular services, interventions and resources (Keil et al. 2006), and can ensure children within the education system are protected

by relevant legislation (e.g. Department for Education and Skills 2001; Disability Rights Commission 2006).

The benefits of spending time with other people similarly labelled should also be recognised by adults involved, and opportunities facilitated for this by EPs and other related professionals, for instance through implementing autistic spectrum social groups. Findings suggest too that some autistic spectrum diagnosed individuals would benefit from extra help to maintain their social relationships. There is also a need for EPs and all adults involved with diagnosed young people to be particularly sensitive to their challenging feelings of worry, anxiety and / or anger.

Nearly all-current participants preferred their secondary (specialist) school to primary school. There are a number of possible interpretations of this. For instance, four out of five participants attended a mainstream primary school, which may indicate that for this small group of young people, the greater expertise provided at their specialist secondary school outweighed the benefits of being included in a mainstream environment. Furthermore, knowledge and experience of the autistic spectrum is now increasing dramatically in mainstream schools – it was possible that this was not the case when current participants attended their mainstream primary schools. Alternatively, by the time they reached secondary school, participants and their families were probably by now more used to living with the autistic spectrum label, thus possibly generally rendering the educational experience easier. Regardless of these possible explanations however, EPs need to be aware that placement issues are not black and white and that, as evidenced in the current study, the merits of specialist autistic spectrum provision cannot be discounted.

Theoretical models and EP Practice

With regard to the relevance of theoretical models and disciplinary perspective for EP practice, current findings suggest that positivist developmental psychology research is of some use in highlighting autistic spectrum impairment difficulties. However the dangers of forming generalised assumptions and stereotypes around individuals should be strongly highlighted by EPs to the relevant professionals and

parents. As such it could be argued that medical and traditional developmental psychology perspectives - when used as a conceptual framework to inform EP practice - are of limited value in understanding the unique perspectives and life experiences of young people themselves. Such perspectives are also limited by a lack of reference to important disabling social and environmental factors and are constrained by a narrow focus on impairment constructed as deficit and disorder. As suggested through the life-stories, a social model of disability is particularly relevant to the work of an EP in order that barriers faced by young people in their social and learning environments can be identified and challenged collaboratively with the adults involved. Moreover, EP practice that is underpinned by an epistemologically social constructivist stance holds promise with regard to challenging unhelpful social constructions around the autistic spectrum label. It is important to highlight that such unhelpful constructions may exist on the part of EPs themselves (as was reflected in the experience of the current researcher), highlighting the importance of a need for continual and ongoing reflexive professional practice when working with children labelled as on the autistic spectrum (Billington 2006).

The implications of such social views are such that, in place of medical and traditional developmental psychology models, there is a need for applications of alternative social, humanistic, positive and narrative psychology frameworks within the practice of EPs. In this way environmental factors within the lives of young people can be addressed, whilst there is also recognition of the child as a whole being, with the very "normal" human need to belong. In place of a focus on pathology, the assets of children labelled as on the autistic spectrum should also be considered (Billington 2006), whilst Personal Construct psychology approaches (Kelly 1963) ensure that their views remain central during EP assessment and intervention work

However it could be argued that EP work continues to be framed by a "Special Educational Needs" (SEN) discourse to some extent, which is dominated by medical and traditional psychology models of categorisation, labelling and pathology, with little concern for addressing the social barriers faced through oppressive systems (Keil et al. 2006). Such a discourse leaves little pressure on schools to change their practices and learning environments to accommodate children who may be different

(Frederickson and Cline 2002; Keil et al. 2006), raising particular challenges for the EP adopting social views on the autistic spectrum and applying alternative psychological frameworks to their practice.

When working within such a "SEN" discourse, EP practice tends to be casework-driven rather than concerned with systemic factors, co-constructing a discourse of child deficit through the use of assessments often linked with the allocation of resources and provision (Korn 1997). As Korn (1997) describes,

> In its move toward psychometrically informed practice, psychological assessment has largely abandoned its function as a means of furthering understanding about children's lives. It has resulted in a further transformation of the role of psychologist from child advocate to technician.
>
> (Korn 1997, p.29)

Moreover when working within such a discourse, EP facilitation of school-based interventions also tends to be framed by a traditional developmental psychology view of the autistic spectrum. Thus social and learning interventions are either facilitated or directly implemented by EPs, geared at "normalising" children often based on behavioural psychology approaches (Andrews 2006). These include applied behavioural analysis techniques such as those described by Lovaas (1977; cited in Tutt, Powell and Thornton 2006), and Wilkinson (2005), where the emphasis is on changing the child to meet the demands of her environment. Moreover, whilst useful in its highly visual component, the TEACCH approach is also basically behaviourist in orientation (Tutt et al. 2006). Cognitive-based interventions are also sometimes designed by EPs with schools in order to increase a child's "theory of mind" (Greenway 2000). However, as commensurate with traditional developmental psychology models, the conceptual framework of such interventions is one of remedying child deficits, whilst environmental and wider social influences / barriers are ignored.

On the other hand, according to social views of the autistic spectrum which lend themselves to alternative psychological frameworks, rather than focusing on perceived deficits within the child, EPs direct their efforts at ensuring the classroom

and school environment is adapted to the needs of the child. For instance, social ecological theories (Bronfenbrenner 1979) are applied whereby EPs work systemically with schools and families (Provis 1992), whilst support is also targeted at autistic spectrum policy implementation at both school and local authority level. Importantly, teachers, parents and increasingly the wider community are considered as key in finding solutions, rather than individual children in need of being "fixed".

Systemic work with teachers is also carried out through a Consultation framework (e.g. Wagner and Gillies 2001), using for instance a solution- rather than problem-focussed approach (e.g. Rhodes 1993). This is based on a Positive psychology orientation (Seligman and Csikszentmihalyi 2000), underpinned by a social constructivist view of reality to reframe unhelpful perceptions (De Shazer 1985). In keeping also with a Positive psychology orientation, assessments and interventions are also designed to identify and channel the assets of children, avoiding a narrow focus on perceived pathology (Billington 2006; Lasser and Corley 2008),

There are a range of EP-facilitated interventions based on a social model view of the autistic spectrum, whereby the reduction of social and learning environmental barriers is paramount. Such interventions also address the concerns of the humanistic psychology field, whereby children labelled as on the spectrum increasingly feel a sense of belonging. Relevant approaches include "Circles of Friends" (Whitaker, Barratt, Joy, Potter and Thomas 1998; Newton and Wilson 1999), specifically designed to increase inclusion and reduce bullying. Importantly, autistic spectrum-related information should also be shared with peers in order to increase their tolerance of difference (Connor 2000; Gus 2000). With regard to specifically improving the learning environment, mentoring and buddy schemes can be used (Connor 2000) as well as collaborative learning approaches with peers (Grey, Bruton, Honan, McGuinness and Daly 2007). All such approaches would however need to be linked to the individual needs of the young person. As also portrayed in the life-stories of the current study, each child labelled with autistic spectrum is highly unique (Connor 2000), as indeed is the case with all children.

EP Practice and the Individual Child

As highlighted in ***Chapter Two: Literature Review***, to the researcher's knowledge there is no other research designed solely to gain the perspectives of young people labelled as on the autistic spectrum. It could be argued that this is also reflected within EP practice, whereby the child's voice is often deemed secondary to the voices of more powerful others – including those of EPs themselves. As described by Korn (1997), EPs can sometimes lose sight of the fact that their primary client is the child herself.

As such, and assuming a belief in the centrality of young people's views, EP practice should avail itself of techniques stemming for instance from Personal Construct psychology (Ravenette 1999; Beaver 2003) and Solution Focused Therapy (Rhodes 1993). These aid understanding of the world-view of the child and help improve understanding of their constructions of reality, which should be used to inform subsequent interventions. As reflected in the current research process, careful thought needs to be given to the rights of children and confidentiality of their views during EP practice. For instance, the EP should consult young people over whether they actually wish their views to be shared with others.

Also with regard to individual young people, and as portrayed in the current study, information given to them about their diagnosis helps to increase levels of self-understanding (Whitaker 2006). As such special consideration should be given to decisions around information disclosure as tailored to individual circumstances. As shown in the current study, such decisions cannot be made without collaboration with the child's family, working alongside their constructions of the autistic spectrum as well as those of the school.

Although a strong focus on social and environmental barriers was revealed within the current study, the lived experience of autistic spectrum impairment also emerged. This was particularly evident in the area of relationships. As such and alongside social interventions described above, individually based interventions can also be facilitated by EPs. However these should be carried out with the aim of improving individual coping resources *if deemed appropriate by the young person in question*,

rather than with the goal of "normalisation" of diagnosed young people. For instance a "Social Story" approach can be used to explore a range of possible responses to specific social situations experienced as problematic (Humphrey and Lewis 2008). Interventions could also include direct work using role-play and coaching either individually or in groups, around challenging social situations (Connor 2000), as well as specific input on building and maintaining friendships (Gutstein 2003).

Finally and with regard to the learning environment in particular, EPs need to support teachers to ensure appropriate adaptations are made within classrooms as well as through teaching methods, in order to cater for any individual impairments such as sensory difficulties, problems understanding language or difficulties with changes to the routine.

EP Practice and Life-Stories

Participants in the current study highlighted ongoing experiences of worry and anxiety, bringing to the fore the therapeutic role sometimes adopted by EPs. The process of creating the life-stories themselves held therapeutic value for the participants. As described by Korn (1997) with regard to narrative psychology approaches within EP practice,

> In constructing the narrative of a child's life through the process of assessment, psychologists become engaged as advocates for children...Rather than uncovering immutable truths, the process of psychological assessment can contribute to understanding children's lives by creating a coherent and plausible story of children's lived experience that enables others to act on their behalf.
>
> (Korn 1997, p.35)

As such the life-story method itself is relevant as an intervention for children labelled as on the autistic spectrum, either directly undertaken or facilitated by EPs. Through working with young people to create their life-story, opportunities are created not only to explore their experiences, perspectives and challenges as portrayed in the

current study, but when followed through as an intervention, opportunities can be created to allow "positive storytelling and / or alternative narratives" to be created (Goodley et al. 2004:169). From a counselling and psychotherapeutic angle there are clear links between the life-story method and the field of narrative therapy (e.g. DeSocio 2005; McLeod 2006). As described by DeSocio (2005), the content of life-stories often reflect the dominant self-beliefs of their narrators which in turn influence their behaviour. Other more helpful self-constructions may not have yet been considered. By working with individuals to change the language in their life-story, new meanings for their life can be considered thus creating the potential for new stories to be lived. Moreover, narrative therapy approaches diverge from traditional psychological therapies in their relative lack of psychological analysis and interpretation of individuals. Rather the ways in which their life is construed by the individual is taken as a starting point for subsequent collaborative and therapeutic work (McLeod 2006).

It could be argued however that both within EP practice, as well as within the busy school environment, the time taken to undertake life-story work may serve as a significant obstacle. Aside from the constraints of time, incorporating narrative approaches into psychological practice also presents epistemological challenges when working within professional discourses dominated by traditional psychology models (Crossley 2007). However it is only by spending quality time with young people labelled as on the autistic spectrum that unhelpful social constructions around these young people can be reframed.

Narrative Approaches and Community Psychology

Current findings suggest that participants had little social contact with peers after school, and lacked involvement with their local community. This is of increasing relevance to EPs, the focus of whose role is beginning to widen to encompass a community orientation (MacKay 2006; Stringer, Powell and Burton 2006). In place of a traditional psychology focus on deficit and disorder as applied within a narrow focus on the school environment, a community psychology approach is underpinned by both humanistic and social psychology principles (Stringer et al. 2006), whereby

again the child is considered within the wider systems of family and community, as well as school. Viewed from this perspective, EPs work together – often as part of a multi-disciplinary team - with schools, families and increasingly the voluntary sector to ensure the needs of young people labelled as on the autistic spectrum are met within the wider contexts of their lives as a whole.

As highlighted by Goodley et al. (2004), there are strong links between the life-story method and the field of community psychology. Both life-story work and community psychology are considered to share a mutual allegiance to emancipatory paradigms, whereby work is undertaken with marginalized individuals who are considered experts on their own lives, and whereby the goal is to facilitate social change (Goodley et al. 2004). Although referring to life-story work within a research framework, it could be argued that Goodley et al's (2004) views below are also highly relevant to the practice of EPs as emerging community psychologists:

> Following the tenets of a liberating view of community psychology, the aim here is to invite people into research who are so often the distant audiences of our research. Historically psychology, for example, has created a body of knowledge on people, about people, with the aim of restoring normality or betterment to people's lives. Potentially, and in contrast, researching life stories demonstrates an approach to emancipatory research, which locates research paradigms – such as psychology – back in the community. Now located, our traditional passive recipients of psychological theory become co-researchers, and theoreticians, challenging the distinction between expert and client, psychologist and participant and researcher and researched.
>
> (Goodley et al. 2004, p.179-180)

Final Reflections

The themes emerging from the study will go some way to moving on the agenda for social change within the autistic spectrum field, through the practice of professional educational psychology. As such, the study will conclude with the words of a practising EP who himself has an autistic spectrum label:

> There needs to be more reliance upon the practices and findings of social psychologists, and less emphasis on the clinical obsession with statistical norms. There must be a shifting of values within clinical and educational psychology to take into account the autistic individual's right to be himself and determine his own life. Humanistic principles might, alongside the social psychological understanding of individual difference, facilitate such a change. The problem is that – whilst ever it is a system run by the so-called 'normal' individual (and for that sort of individual) – that change will never come.
>
> (Andrews 2006, p.105)

Through the life-stories of the current study and associated researcher reflections, some of the qualitative features of working with each young person have been conveyed, together with an over-riding researcher experience of the participants as unique and whole human beings in their own right, irrespective of diagnostic labels. Despite sharing the autistic spectrum label, the individual differences between participants in terms of their personalities, temperaments, ways of interacting both with me and with the research process were significant. As a direct consequence of undertaking this research, I hope I will no longer see the label in place of the person. Rather I will seek to remember that young people are people first and foremost, and any additional labels they have are secondary to this.

Moreover and also as a result of carrying out the present study, the anxiety that I initially felt around working with young people diagnosed specifically with autistic spectrum, has dissipated. I learnt that, through placing the young people at the heart of the research and taking the directional lead from them as far as possible, my experience of interacting with them became extremely rewarding. I will seek to incorporate this lesson into my ongoing practice as an EP when working with young people with an autistic spectrum label.

The experience of carrying out the research within a narrative inquiry framework was at times a journey of discovery. However my sense also is that it is enormously flexible, enabling the inclusion of participants who might otherwise be excluded from more traditional research frameworks. Moreover I believe the narrative inquiry field holds great promise when specifically used to explore the experiences of young people labelled with autistic spectrum.

APPENDIX 1

Letter to Headteacher and Centre Manager

Norah Fry Research Centre
3 Priory Road
Bristol, BS8 1TX
Tel: 0117 331 0987
Direct: 0117 331 0977
Fax: 0117 331 0978
E-mail: John.Franey@bristol.ac.uk
Web:
www.bris.ac.uk/Depts/NorahFry/

Norah Fry Research Centre Ethical Committee Representative (university contact in event of ethical concerns):
Beth Tarleton.
Email: beth.tarleton@bristol.ac.uk.
Tel: 0117 3310976

Sian Clark, Researcher
52, Stean Bridge Rd.
Bradley Stoke
Bristol
BS32 8AH

Tel: 07748624924

Dear Headteacher / Centre Manager

I am writing to seek your assistance in making contact and undergoing doctoral research with some students in your school. The purpose of the research would be to deepen our understanding of the life-experience of young people who have been given the label of autistic spectrum. It is often difficult to understand how young people see the world, but by giving them a voice, we can increase the possibility of providing support for them in ways that are relevant and useful. This will enhance educational and psychological provision and intervention both locally and nationally.

I would like to work individually with between 5-8 young people from your school, in order to jointly create their life story with them. I would firstly like to send out information letters via yourself to all parents who are most likely to be interested and whose children, through prior discussion with yourself, would be able to give informed consent to the research. If you were able to also send out a letter in support of the research to these parents at this stage, this would also be very useful. Once they received this letter, and having talked it through with their son or daughter, the parents would be given the option of expressing interest either to you or I as they wish. I would then make the final selection of participants myself, trying if possible to ensure a spread of age, gender and ethnicity.

The research would subsequently entail each young person meeting with me on three separate occasions, for between half-an-hour and an hour a time. There will be a week between each individual interview. The interview will be terminated if the young person indicates they would like to stop. During these sessions we would together create their individual life story. Each young person would decide how this would be done, e.g. through writing, photographs, artwork, drama, video, etc. When creating the life-story, a false name would be used for each young person, as well as for any other people identified by the young person in their life-story. The school would also be given a false name. This is to ensure that all the young people, as well as your school and its population, remain anonymous throughout the research. Each young person would keep the life-story they have created. Once involved, the young people would still be free to withdraw from the research at any point, and their information from that point would not be used. The anonymised life-stories would subsequently be used as a basis for a discussion in my doctoral thesis.

I hope to meet with you soon in order to discuss this further.

Yours sincerely,

Sian Clark

BA (Hons); PGCE; MEd. (Psychology of Education); Educational Psychologist in Doctoral Training, University of Bristol

APPENDIX 2

Headteacher / Centre Manager Consent Form

University of BRISTOL

Norah Fry Research Centre
3 Priory Road
Bristol, BS8 1TX
Tel: 0117 331 0987
Direct: 0117 331 0977
Fax: 0117 331 0978
E-mail: John.Franey@bristol.ac.uk
Web: www.bris.ac.uk/Depts/NorahFry/

Tel: 07748624924 (Sian Clark, Researcher direct)

"Life-Stories of Young People Labelled with Autistic Spectrum"

Please tick or cross each box if you agree with the statements.

You have explained the purpose of the research project to me

verbally ☐ on paper ☐ other method ☐

I confirm that I understand and agree with the reason for, and method of the research. ☐

I give my permission for the researcher to go ahead with this researcher ☐

Signed .....Date .....

(Headteacher of special school)

Signed .....Date .....

(Manager of specialist centre provision)

APPENDIX 3

Parent Information Letter

Norah Fry Research Centre
3 Priory Road
Bristol, BS8 1TX
Tel: 0117 331 0987
Direct: 0117 331 0977
Fax: 0117 331 0978
E-mail: John.Franey@bristol.ac.uk
Web:
www.bris.ac.uk/Depts/NorahFry/
Tel:07748624924(SianClark,
Researcher direct)

Norah Fry Research Centre Ethical Committee Representative (university contact in event of ethical concerns):
Beth Tarleton
Email: beth.tarleton@bristol.ac.uk.
Tel: 0117 3310976

Sian Clark, Researcher
52, Stean Bridge Rd.
Bradley Stoke
Bristol
BS32 8AH

Tel: 0774862492

Dear Parent

I am currently undertaking doctoral research into the life-stories and experiences of young people who have been given the label of autistic spectrum. It is often difficult to understand how young people see the world, but by giving them a voice, we can increase the possibility of providing support for them in ways that are relevant and

useful. This will enhance educational and psychological provision and intervention both locally and nationally.

Specifically, I would like to deepen our understanding of how these young people see their own lives. Your child and I would do this together by developing their life-story according the individual needs of your child. I would have met with you first to discuss with you the best way for me to communicate with your child and how best to design the sessions. If you were willing for your child to become involved in this research, it would then involve your child meeting with me on three separate occasions, for between half-an-hour and an hour a time, during which time we would together create your child's life story. There would be a week between each interview. The interview would be terminated if your child indicated that they had had enough. Your child would decide how their life-story would be created, e.g. through writing, photographs, artwork, drama, video, etc. When creating the life-story, a false name would be used for your child, as well as for any other people identified by your child in their life-story. The school would also be given a false name. This is to ensure that your child remains anonymous throughout the research. Your child would keep the life-story they have created.

I would then use this anonymised life-story, along with those completed with other young people, as a basis for discussion in my doctoral thesis. Here I would describe how an improved understanding of these young people's life experiences relates to educational and psychological theory, practice and intervention.

If you feel you may be happy for your child to take part in the research, I would be grateful if you would check with your child first whether it may be something they would be interested in themselves. If so, I would be grateful if you would fill out the slip below and return it to the Prospect Centre, for the attention myself, before the end of May.

I will be selecting a final sample of between five and eight young people, and if possible I will try to reflect a spread of ethnicity, age and gender in the sample. As such, it is possible that, having expressed an interest, your child may not be

subsequently selected for the final study. However, if this scenario did take place, with your permission I would keep your name on my list to contact later if possible.

I hope to hear from you soon.

Yours sincerely,

Sian Clark

BA (Hons); PGCE; MEd (Psychology of Education);
Trainee Educational Psychologist (Doctorate in Educational Psychology), University of Bristol.

APPENDIX 4

Parent Consent Form (1)

University of BRISTOL

Norah Fry Research Centre
3 Priory Road
Bristol, BS8 1TX
Tel: 0117 331 0987
Direct: 0117 331 0977
Fax: 0117 331 0978
E-mail: John.Franey@bristol.ac.uk
Web:
www.bris.ac.uk/Depts/NorahFry/

Tel: 07748624924 (Sian Clark, Researcher direct)
Email: sbohana@blueyonder.co.uk

Life Stories and Experiences of Young People Labelled with Autistic Spectrum

Child's name: .....Year group: .....

Please tick or cross each box if you agree with the statements.

You have explained the purpose of the research project to me

verbally ☐ on paper ☐ other method ☐

I confirm that I understand and agree with the reason for, and method of the research. ☐

I give my permission for the researcher to send an information pack to my child. ☐

Signed ..... Date .....

APPENDIX 5

Parent Consent From (2)

University of BRISTOL

Norah Fry Research Centre
3 Priory Road
Bristol, BS8 1TX
Tel: 0117 331 0987
Direct: 0117 331 0977
Fax: 0117 331 0978
E-mail: John.Franey@bristol.ac.uk
Web:
www.bris.ac.uk/Depts/NorahFry//

Tel: 07748624924 (Sian Clark, Researcher direct)
Email: sbohana@blueyonder.co.uk

Life-Stories of Young People and Adults Labelled with Autistic Spectrum

Child's name: .....Year group: .....

Please tick or cross each box if you agree with the statements.

You have explained the purpose of the research project to me

verbally ☐ on paper ☐ other method ☐

I confirm that I understand and agree with the reason for and method of the research. ☐

I give my permission for my child to be involved in the research project. ☐

I understand that I can withdraw my child from participating. If this is the case, their information will not be used from that time onwards. ☐

I understand that my child will collaboratively create his or her life-story with the researcher. This may involve using a tape-recorder, camera or video-camera to create the life-story, depending on how the child wishes to approach this. ☐

I understand that the life-story will remain confidential to my child, and that they will keep their life-story. I understand that my child may not wish to share their life-story with me. The researcher would only break the confidentiality of my child in the very unlikely event that she considered my child or others to be at risk. ☐

I understand that the researcher will digitally record the life-story sessions for her data collection and transcription purposes. ☐

I give permission for the data collected about my child to be used:

As part of a presentation of the findings by the researcher, where my child cannot be identified ☐

As part of a doctoral thesis written by the researcher, where my child cannot be identified. ☐

In the form of quotations or descriptions in the above, where my child cannot be identified. ☐

By other researchers in other organisations, where my child cannot be identified. ☐

Signed .....Date .....

APPENDIX 6

Participant Information Sheet

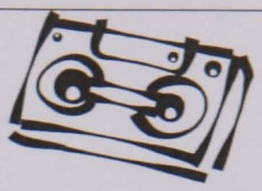
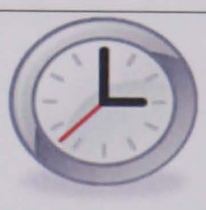
Norah Fry Research Centre
3 Priory Road
Bristol, BS8 1TX
Tel: 0117 331 0987
Direct: 0117 331 0977
Fax: 0117 331 0978
E-mail: John.Franey@bristol.ac.uk
Web:
www.bris.ac.uk/Depts/NorahFry/
Tel: 07748624924 (Sian Clark, Researcher direct)
Email: sbohana@blueyonder.co.uk
Norah Fry Research Centre Ethical Committee Representative
(University contact in event of ethical concerns):
Beth Tarleton
Email: beth.tarleton@bristol.ac.uk.
Tel: 0117 3310976

I am doing some research. This is because I want to learn how to work better with young people.

- **I would like to understand how young people see their own lives,**
- **I would like to help them to create their own life-story.**
- **I will use what I find out to help teachers and other professionals make young people's lives better.**
- **I want young people like you to take part in research. You are the expert on your life!**

I would like to come and talk to you about your life and to help you create your own life-story.

Important things for you to know:

We could use a tape recorder, camera or video camera if you would like to create your life-story in this way. This will not be listened to or watched by other people, unless you want it to be. We could also tell your life-story using art, writing, acting or anything else that you would like to use. You are in charge of how to make your life-story. I will also record our sessions using a digital recorder. This will make sure that we use your words, pictures or actions to make your life-story. It will also help me remember what we say.	
We will meet about three times to create your life-story. Each time we will spend between half-an –hour and an hour to create your life-story. There will be a week between each interview.	
When we create your life-story we will use a pretend name for you. We will use a pretend name for your school. We will use a pretend name for any other people you may talk about. This is called anonymity. This is because I want you to be really honest about your life-story.	
You will keep your finished life-story. I will go away and write something for my university about your life-story. I will share what I write with teachers and other professionals.	
It is up to you whether you want to do this. If you do decide to do it, you can stop doing it at any time. You will create your life-story yourself, with my help if you need it.	

We are likely to have a fun time doing this. It is very unlikely that you will feel bad, but if you do, we can call your parent to help. Your parent will know that s/he must not tell anyone else about your life-story.	

What you need to do!

If you do want to be involved you need to complete the consent form.

If you, or your parents want to know anything else before you decide, feel free to phone or email me.

APPENDIX 7

Participant Consent Form

University of BRISTOL

Norah Fry Research Centre
3 Priory Road
Bristol, BS8 1TX

Tel: 0117 331 0987
Direct: 0117 331 0977
Fax: 0117 331 0978
E-mail: John.Franey@bristol.ac.uk
Web:
www.bris.ac.uk/Depts/NorahFry/

Tel: 07748624924 (Sian Clark, Researcher direct)
Email: sbohana@blueyonder.co.uk

Name: .....

School: .....

Year group: .....

Please tick each box if you agree with the statements.

I understand what this research is about. ☐

I understand why I am making my life-story with Sian. ☐

I agree to take part in the research. ☐

I understand that I can leave the project at any time. If I do my story will not be used. ☐

I understand that we may use tape recorders, cameras or video-cameras or anything else I would like, to create my life-story. ☐

I understand that Sian will also digitally record the sessions, so that she remembers everything we say. ☐

We will use false names for me, my friends, any other people, and my school.
Only Sian and I will know it is my life-story. I can share my life-story with others myself if I choose to, but Sian will not. ☐

Sian will try to make sure what we do is fun. It is unlikely I will become upset. If I do get upset, Sian can call my parent to help. ☐

There is only one reason Sian might tell someone else about my life-story. This is if she thinks someone is hurting me in my life, or if I am hurting someone else. This is extremely unlikely. ☐

I give permission for my life-story to be used:

- As part of a presentation by Sian to other adults, where no-one will know who I am. ☐

- As part of a report by Sian, where no-one will know who I am. ☐

- In the form of quotations or descriptions, where no-one will know who I am. ☐

Signed.....

Date .....

APPENDIX 8

Key Areas for Exploration

(Sent to parents for information)

University of BRISTOL

Norah Fry Research Centre
3 Priory Road
Bristol, BS8 1TX
Tel: 0117 331 0987
Direct: 0117 331 0977
Fax: 0117 331 0978
E-mail: John.Franey@bristol.ac.uk
Web:
www.bris.ac.uk/Depts/NorahFry/

Tel: 07748624924 (Sian Clark, Researcher direct)

In the sessions we will aim to cover these key areas.

Friends

A best friend?

Friends at home

Friends at school

Adult friends

Peer friends

Any friends from when they were younger?

Pets

Is there one?

What's it like for them to have a pet?

Would they like a pet, if so what kind?

What's special about their pet?

Free time

What do they do when they are not at school?

Is this what they would like to do?

What would they like to do?

TV

Favourite TV programme?

Computers

Favourite computer activity?

Family

Brothers, sisters, parents, grandparents, etc.

Favourite family members

Any family members that are tricky for them?

Any others they would like?

Any special relationships?

School

Favourite activity at school?

Anything they don't like?

Favourite teacher / adult?

Getting to school

Getting home after school

Hobbies

Music

Computer

What I wear

My special things

Any special interests

APPENDIX 9

Plans for Visual Resources during Life-Story Sessions

Visual prompts used with all participants

- Visual prompts to explain notion of "choice" over life-story format e.g. book; film; photographs; artwork; a spoken story, etc.

Other visual resource plans, not subsequently required

- Visual time-line or "life-plan" to explain temporal nature of life-story, with a beginning, middle and end.

- Visual symbols and pictures to represent each key area for exploration. These could then be physically placed on the "life-plan" as each key area is explored to create the life-story.

- Use of photos provided by parents to visually mark each part of the life-story.

- Use of one plan for good experiences and one for bad experiences.

APPENDIX 10

Narrative Analysis of Two Autobiographies published by Adults Labelled with Autistic Spectrum

This study was also submitted as a Research Methods Assignment to Bristol University, January 2009. The original assignment has been slightly adapted for the purposes of the current appendix.

Part One: Background and Rationale

Introduction

The following is an account of one method of analysing two autobiographies written by adults with the autistic spectrum label. Its purpose was to inform the main study which would consist of a set of life-stories, created collaboratively with young people with the autistic spectrum label. This study of two published autobiographies was undertaken as an exploration of how best to analyse narrative material pertaining to life experiences.

Much of the epidemiological research into the autistic spectrum is undertaken from a realist ontology and positivist epistemology. In contrast, there is little interpretivist research undertaken from a nominalist stance, with regard to gaining a deeper understanding of the life experience generally of children or adults with the autistic spectrum label. In summary, if one assumes that the very basis of impairment categories has to be questioned, one way of doing this is to explore the insights and life experiences of the individual people that are "categorised". It was with this in mind that the field of autobiographical writing was first considered.

Narrative Analysis and Autobiographies

A number of psychologists have applied a narrative analysis approach to the analysis of written autobiographies in general (e.g. Bruner 2001; Freeman and Brockmeier 2001; Freeman 2004). Freeman (2004) considers that autobiographies are usually

written with a particular purpose in mind, in order to teach their audience something new. Likewise, Freeman and Brockmeier (2001) describe how, through writing autobiographies, narrators imbue their life-stories and experiences with a meaning that can only be done in hindsight. In this sense, it could be argued that autobiographical writing is a purposive act, undertaken to inform, teach and facilitate new insights on the part of its readers. This psychological perspective regarding the underlying purposiveness of written autobiographies, fits well with one of the aims of the current study, namely for the researcher to learn about the life of people labelled with the autistic spectrum.

There are now a good number of published autobiographies written by adults who have themselves chosen to take on the autistic spectrum label (e.g. Williams 1992; Lawson 1998; O'Neill 1999; Jackson 2002; Grandin 2006; Tammet 2006). Towards the end of one of these autobiographies, the author gives an account of the response of a medical doctor, who reads her autobiography prior to its publication:

> He pointed out that there were many children who had had experiences like mine and that my book may be important in understanding them.
>
> (Williams 1992, p.166)

This statement is central to the rationale for analysing the published autobiographies and the research questions of this early study developed from this rationale. These questions were as follows:

- *How do individual adults with the label autistic spectrum see their own lives and experiences?*

- *How can this be used to inform plans for life-story work with young people who have been given the autistic spectrum label?*

On reading the literature on psychological approaches to the narrative analysis of written autobiographies (Crossley 2000; Brockmeier 2001; Bruner 2001; Freeman

and Brockmeier 2001; Harre 2001; Freeman 2004) it was clear that specific elements and themes were widely considered as relevant to autobiographical writing generally. However, two themes were particularly recurrent: These were firstly the development of "self" or "identity", and secondly the construction of "socio-cultural environment" or "culture". With reference to the former, Bruner (2001:32) considers that specific "turning points" are evident in the written narratives of autobiographers when describing the process of their "self" or "identity" formation. Bruner defines these "turning points" in the following way....

> ....those episodes in which, as if to underline the power of the agent's intentional states, the narrator attributes a crucial change or stance in the protagonist's story to a belief, a conviction, a thought.
>
> (Bruner 2001, p.31)

With reference to the second recurrent narrative theme, Bruner (2001) considers that depictions of "culture" within written autobiographies generally run parallel to their portrayals of the development of "self". Freeman (2001) also highlights the inter-relationship between the construction of "self" and the construction of its surrounding "socio-cultural environment". He comments that,

> The self, and narratives about the self, are culturally and discursively 'situated'....simply put, 'my story' can never be wholly mine, alone, because I define and articulate my existence with and among others....
>
> (Freeman 2001, p.287)

Selected Autobiographies

Two published autobiographies were analysed written by adults who have chosen in adulthood to take on the autistic spectrum (Williams 1992; Holliday Willey 1999).

Liane Holliday Willey was born in 1961 in the US. Her autobiography was published in 1999 when she was 38. The autobiography chronicles the experience of a child growing up with a strong sense of being different from others around her.

However, Holliday Willey's childhood is described as relatively stable despite her difficulties, which she attributes to the fact that she had both family and childhood friends who loved and accepted her for who she was. Presenting as gifted and talented at school, there was no consideration by teachers that her social and communication difficulties, hypersensitivity and obsessional behaviour required any additional support. The diagnosis of her own daughter with Asperger's Syndrome proved to be a real turning point for her, bringing a sense of relief, self-understanding and acceptance that her own sense of "differentness" could at last be explained.

Holliday Willey's autobiography caused some controversy partly owing to the fact that at the time of publication, she had not been formally diagnosed (although later received a formal diagnosis of "Asperger's Syndrome"). Her autobiography also portrays how she has been able to increasingly manage her difficulties over time. It could be argued that this could give false hope to others who have more severe impairments less amenable to amelioration over time.

Donna Williams (author of the second autobiography in the current study) was born in inner city Australia in 1963. She was formally diagnosed as "autistic" in 1990 when she was 29. Her autobiography was published two years later. In contrast to the first author, Williams was brought up in highly abusive family which was continued by others until early adulthood.

As with the previous text, publication of this autobiography also caused controversy, however for different reasons. As a result of the significant abuse suffered by the author as a child, it could be argued that it is consequently difficult to ascertain which individual difficulties were experienced as a result of the child abuse, and which were as a result of autism.

Description of the Data Analysis Process

Early data analysis of the autobiographies involved re-reading both texts several times. The aim of reading these texts was to gain a better understanding of how these adults saw their own lives. It was with this in mind that the tool of narrative

inquiry was subsequently considered for the purpose of data analysis (Reissman 1993; Clandinin and Connelly 2000; Daiute and Lightfoot 2004; Clandinin 2007), since an underlying principle of narrative inquiry is that reality is not external and objective, rather constructed individually by individual people (Reissman 1993). Moreover, the doctoral thesis within which this early study is situated, will seek to improve psychological intervention for children who have been given the autistic spectrum label. In view of this, a psychological approach to narrative analysis was favoured.

A narrative analysis framework was adopted using Bruner's (2001) definition of "turning points" to portray the development of "self", combined with Bruner's (2001) and Freeman's (2001) concept of a "culture" within which this "self" develops (see definitions detailed earlier under ***Autobiographical Research***). Following early readings and re-readings of the two selected autobiographies, two time-lines were created for each autobiography. Recorded verbatim from the text along the first time-line are instances where the narrator's psychological "turning points" appeared to fit Bruner's definition. It should be noted immediately however that this process constituted highly subjective researcher decisions, thus immediately weakening the case for using this type of method of data analysis.

Along the second time-line, constructions of the "socio-cultural environment" / "culture" were also recorded in a similar fashion for each autobiography. Time-lines were then compared and contrasted between the two autobiographies, and any recurrent themes, similarities and differences were noted. (See ***Appendices 11-14*** for the time-lines).

Issues of Validity

Reissman (1993) considers that the validity of narrative analysis is a complex area. Owing to word constraints, it will not be possible to explore such issues in the detail that they warrant, however they will be discussed in depth within the final doctoral thesis as a whole.

With this caveat in mind, two of Reissman's (1993) criteria for evaluating the validity of narrative analysis do merit consideration here, even though they apply to oral rather than textual narrative data. One of these criteria includes the concept of "persuasiveness" (Reissman 1993:65). Reissman considers that the "persuasiveness" of a study which uses narrative analysis can be evaluated according to whether researcher interpretations of the data are backed up with evidence from the data itself, and also whether alternative interpretations of the data are considered. As can be seen in the ***Data Analysis Results (Part Two)*** section below, all results were presented with at least one section of textual data from the autobiography to which those results relate. Alternative interpretations of the textual data were also discussed within ***Discussion of Results (Part Two).***

In addition, the criterion of "pragmatic use" (Reissman 1993:68) is also of relevance here. This involves consideration of whether the study can form the foundation for the future research of others. It could be argued that this early study informs subsequent research to some degree, albeit that of the current researcher at this early stage.

In ***Part Two*** to follow, the narrative analysis of two autobiographies will be presented and relevant discussions and conclusions for the purposes of the current study will be drawn. Finally a reflective critique of this method of data analysis will be offered.

Part Two: Data Analysis

Narrative Analysis Results

Autobiography (1): Pretending to be Normal, Holliday Willey (1999)

"Turning Points"

The timeline constructed for the purposes of data analysis was scrutinised in detail. It was noted that the "turning points" in Holliday Willey's account could possibly fit Bruner's (2001) definition in Autobiographical Research (Part One) above, where a change in the narrative plot occurs as a result of a change in the narrator's belief or mental state. The most defining "turning point" in the autobiography can be seen when, following her daughter's diagnosis with Asperger's Syndrome, she finally identifies herself with a label which explains a life-time of difficulties.

> Though it has taken thirty-eight years, I cannot express what a relief I feel to finally 'get' me.
>
> (Holliday Willey 1999, p.17)

Another major "turning point" occurs during the period when the narrator leaves home to go to university. Here the narrator describes how, following a very difficult transition, she slowly begins to pull herself out of a deep sense of isolation and fear:

> Ever so slowly I began to find ways to help myself deal with the struggles I faced.
>
> (Holliday Willey 1999, p.57)

and soon after,

...I found I cared less about the differences that kept me from figuring people out.

(Holliday Willey 1999, p.59)

The final significant "turning point" occurs when, following the diagnosis of her own daughter with Asperger's Syndrome, Holliday Willey realises she herself has also lived with individual difficulties that could be explained by this label. For her, this realisation comes with a sense of huge relief, finally putting an end to her psychological struggle:

> I had finally reached the end of my race to be normal. And that was exactly what I needed. A finish – an end to the pretending that had kept me running in circles for most of my life.
>
> (Holliday Willey 1999, p.112)

"Socio-Cultural Environment"

The "socio-cultural context" or "culture" (Bruner 2001; Freeman 2001) within which these personal "turning points" are set, represent a parallel narrative thread within the current autobiography. For Holliday-Willey, the culture in which she grew up is revealed at times as being cruel in its attitudes and behaviour. For instance, she describes how:

> Children with autism ....were institutionalised, with no hope for a better tomorrow. So everyone believed.
>
> (Holliday Willey 1999, p.30)

Fortunately, the narrator escapes this harsh fate, partly on account of having been born to parents who accept her for who she is and partly owing to her lack of associated learning difficulty. Whilst some of these factors protect Holliday Willey from a life-time of institutions, they also count against her, as her less obvious individual needs are consequently neither recognised nor addressed during her schooling....

> Only those students with extreme special needs were typically identified and assisted.
>
> (Holliday Willey 1999, p.33)

Within her ongoing narrative, Holliday Willey constructs a present-day society, which still continues to harbour a vestige of these rigid attitudes:

> What I wish for is a cure for the common ill....that makes people compare themselves to a normal that is measured in terms of perfect and absolute standards, most of which are impossible for anyone to meet.
>
> (Holliday Willey 1999, p.121)

Her wish instead is for a society which....

> ...continues to break the boundaries of normal...and then, maybe then, the world really will welcome all people.
>
> (Holliday Willey 1999, p.75)

Autobiography (2): Nobody Nowhere, Williams (1992)

"Turning points"

The autobiographical timeline was again scrutinised for significant "turning points" (Bruner 2001). For Williams, significant "turning points" particularly within the first half of her life-story, tend to be facilitated by significant others, who act as a "catalyst" for such episodes. For instance, when reflecting on the physical and mental abuse she suffers at home by her mother, Williams describes how a teacher finally enables her to build up courage to ask for help:

> ...even when he raised his voice, I could still sense his gentleness. He was the first teacher at that school to whom I had made an effort to explain what was happening at home.
>
> (Williams 1992, p.48)

Later, a psychiatrist called Mary, also proves a significant influence on Williams in facilitating another "turning point:"

> Mary was to become the most important mental influence on my life…
>
> (Williams 1992, p.92)

As Williams' autobiography progresses, significant "turning points" have as their focus intrapersonal rather than interpersonal relationships. Williams experiences a growing connection with her own sense of "self" which exists independently of other people. For instance she describes how:

> …I began to catch glimpses of my true self.
>
> (Williams 1992, p.110)

Over time this develops into a more secure and stable experience of "self", culminating in an ultimate "turning point" where,

> I finally felt at home within myself within 'the world.'
>
> (Williams 1992, p.160)

As with Holliday Willey (1999) above, discovery in adulthood of the autism label also constitutes a significant "turning point" for Williams. However here, a rather more "mixed picture" is presented here:

> Perhaps this was the answer or the beginning of finding one. I looked for a book on autism. There upon the pages I felt both angered and found.
>
> (Williams 1992, p.165)

and also,

> The label would have been useless except that it helped me to forgive myself and my family for being the way I was.
>
> (Williams 1992, p.170)

"Socio-Cultural Environment"

As with Holliday Willey, there is a clear narrative theme of society's perceptions and "culture" which permeates her childhood through to her early adult years. This reveals a society limited by its need for a cultural "norm:"

> People seemed so ignorant in their self-assured black-and-white conception of 'normality.'
>
> (Williams 1992, p.146)

And, as reflected in the words of a childhood peer.

> You're mad....Why didn't you just try to talk, like normal people?
>
> (Williams 1992, p.36)

The heavy sarcasm used by Williams below, serves to emphasise her sense of growing injustice towards the culture and society in which she grows up:

> These 'helpful' people were trying to help me to 'overcome my ignorance' yet they never tried to understand the way I see the world.
>
> (Williams 1992, p.78)

Williams cleverly uses characters within her narrative as a kind of "mouthpiece" against which she contrasts the prevailing socio-cultural attitudes. Through these characters, Williams raises the possibility that it may be society itself that has something to learn from people like her, rather than the other way round:

> Every so often...someone would wonder whether others had something to learn from me in trying to understand my differentness.
>
> (Williams 1992, p.146)

and likewise through another character:

> 'We think it is we who have to teach autistic people,' Kath said, 'Now I see it is us who have so much to learn from them.'
>
> (Williams 1992, p.172)

Discussion of Results

Similarities and Differences between Autobiographies

Both autobiographies portray psychological "turning points" (Bruner 2001) as crucial elements within the process of the development of "self". Holliday Willey and Williams both use "turning points" to enable them to make sense of difficult life experiences, and in both cases, their ultimate "turning-point" is one of self-understanding and self-acceptance. As such, their constructions of an emerging sense of 'self,' and associated "turning points", serve to create a story which is incrementally progressive and improving over time (Gergen 2001:254)

Holliday Willey's "turning points" appear as relatively free from the influence of other people (other than indirectly, as in the case of her daughter's diagnosis and her own subsequent realisation). For Williams in contrast, the role of significant others during these "turning points" is greater, as in the case of the teacher and later the psychiatrist who both play a significant role in facilitating an individual "turning point".

There could be several reasons for this qualitative difference in the authors' experiences of "turning points". Firstly, during her autobiography, Holliday Willey

describes her family and circle of friends during her childhood and teenage years as very accepting and supportive. As a result of more positive social experiences in her earlier years, it is possible that she has less of a need for others to facilitate her psychological "turning points" when challenges are met later on. By then, a foundation has been laid by others on which she can draw. Williams on the other hand, describes a shockingly abusive childhood, suffering physical and psychological cruelty by her parents in early childhood, continued by others right through to her early adulthood. As such, her need for the compensating positive influence of others could potentially be greater, in her struggle for the development of "self". Alternatively, and/or additionally, individual and temperamental differences between narrators could account for some of the differences in their respective portrayals of "turning points" within their respective life-stories.

Yet it is nonetheless noteworthy that, for both authors, a strong identification with the label of autism in early adulthood comes as a welcome release, helping both to reach their final defining "turning point" where they accept themselves for who they are. In this sense, it is a medical label which ultimately facilitates the positive end to their life-story. This highlights the extreme complexity of the issue of medical labelling and diagnosis. As argued at the outset, the danger of a medical diagnosis discourse is that "individual experience" is marginalized. Yet it is this very discourse, which ultimately provides a sense of relief for the authors.

It is however noteworthy that there are qualitative differences between the authors' experiences of their identification with a medical label. For Holliday Willey, her discovery of the autism label is described only positively. For Williams in contrast, her discovery of the autism label is more mixed. Again, such differences in these narrators' accounts could be explained by the differences in their early family experiences. For Williams in particular, the process of unravelling the effects of autism from the effects of her childhood abuse can only be considered as hugely challenging. Alternatively, interpretive differences between the two authors relating to the autism label could also mirror ongoing socio-cultural debates around medical categories such as autism. Whichever interpretation is favoured, the inherent complexities and contradictions of the processes surrounding medical diagnoses are

clear. As such, these issues will be revisited further within the doctoral thesis as a whole.

Although both narrators portray to differing degrees a sense of value in their identification with the autism label, both share a strong indictment of the socio-cultural fixation on a concept of "normality". This fixation by society poses significant challenges for both narrators in their struggle to develop a sense of "self". Interestingly, whilst both wish for a society which is truly inclusive of all people, each narrator perceives the benefits of this possibility slightly differently. For Holliday Willey, the main reward of a truly inclusive society would be that everybody felt welcome. Williams on the other hand seems to go one step further, suggesting that people with the autistic spectrum, are themselves in a position where they have something uniquely important to teach society as whole.

Reflections and Conclusions

Benefits of Data Analysis Approach

This approach to data analysis has answered the first research question of this preliminary study to some extent. For both autobiographers, the development of a sense of "self" has been crucial in enabling them to perceive their own life in a way which is ultimately triumphant. In addition, psychological "turning points" within their life-stories are constructed as important milestones in this process.

With regard to using these findings to inform plans for life-story work with young people, the following conclusions could be tentatively drawn: Firstly, it may possibly be useful for the researcher to tease out any "turning points" within their life-experience as described by the young person. Moreover, with regard to the autism label itself, the study has highlighted to some extent the complexities and contradictions inherent with the discourse of medical diagnosis. As such, researcher efforts will be made to remember that each young person's relationship with a label

such as the autistic spectrum is likely to be highly unique and individual, as was clearly portrayed in the autobiographies analysed.

Limitations of Data Analysis Approach

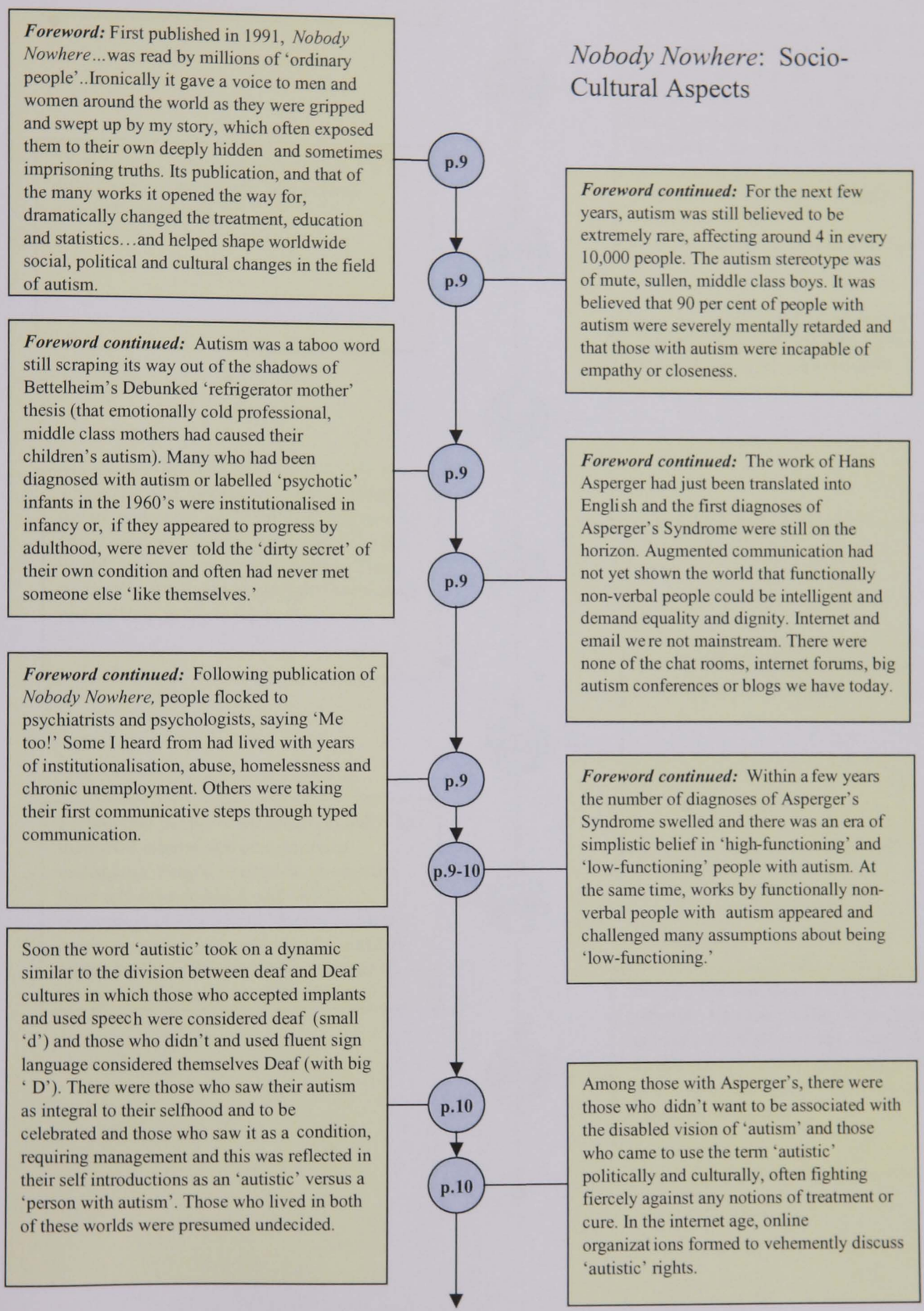
The method of data analysis employed nevertheless has several limitations. In particular there are researcher concerns with regard to the use of timelines for the purpose of data analysis. It could be argued that timelines such as these constrict and segment the data in such a way as to lose the richness and breadth of the lived experiences that are being portrayed. When considering the future analysis of collaboratively created life-stories with young people, using time-lines in this way could deny the very "personhood" of the young people involved as well as the "essence" of their individual life-stories, constraining their words into pre-defined set categories.

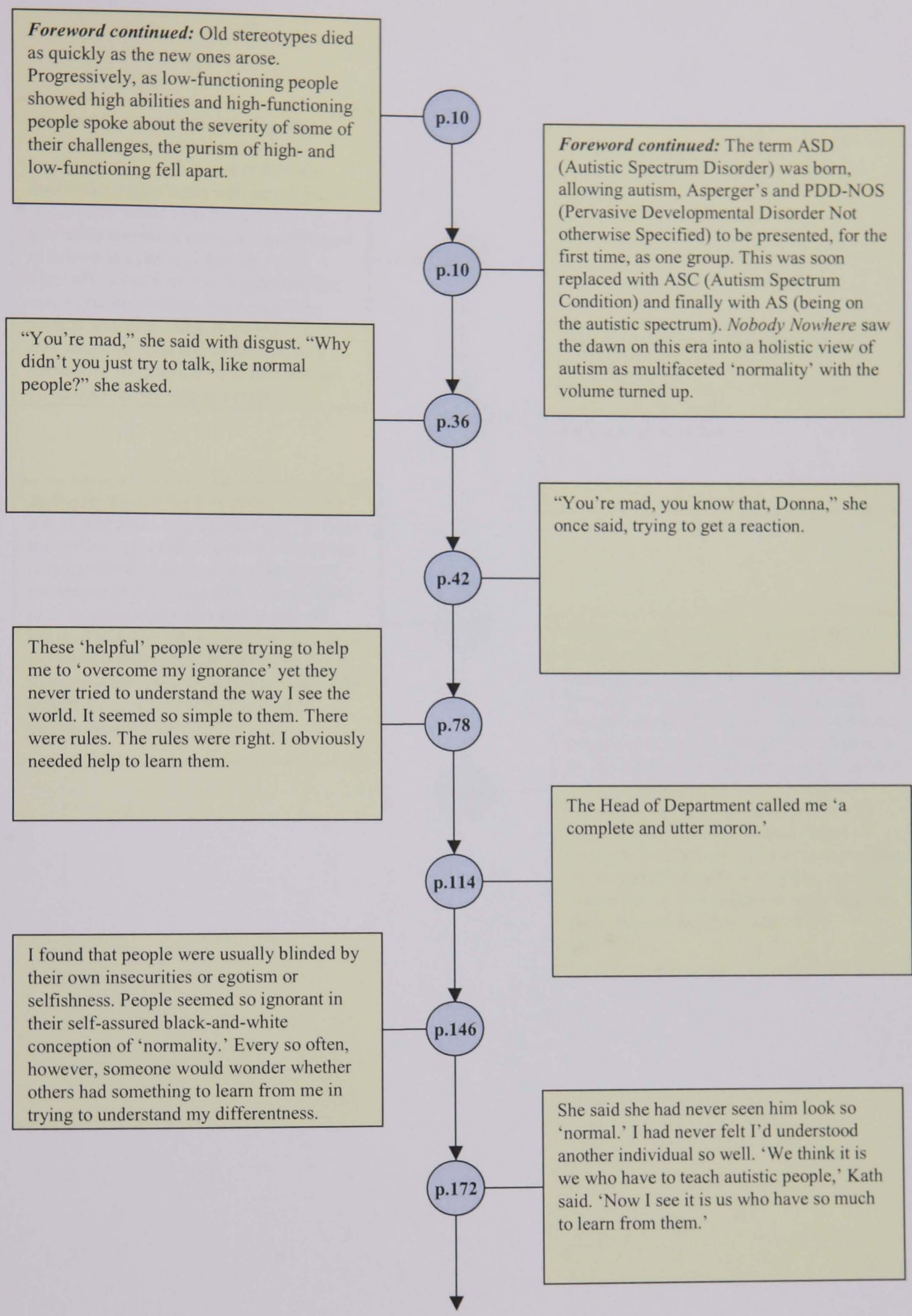
Additionally, the time-lines do not allow the researcher to take a view of the autobiographies as whole entities, rather they fragment the stories into a rigid methodological framework. In this way the time-lines represent a deductive approach to data analysis with a tendency towards a realist ontology. This is in contrast to the underlying principle of narrative inquiry whereby reality is socially constructed by individuals. As the current study aimed to use a social constructivist epistemological basis for data analysis based on the narrative inquiry tradition, it could be argued that this method of data analysis was not true to the study's overall aim.

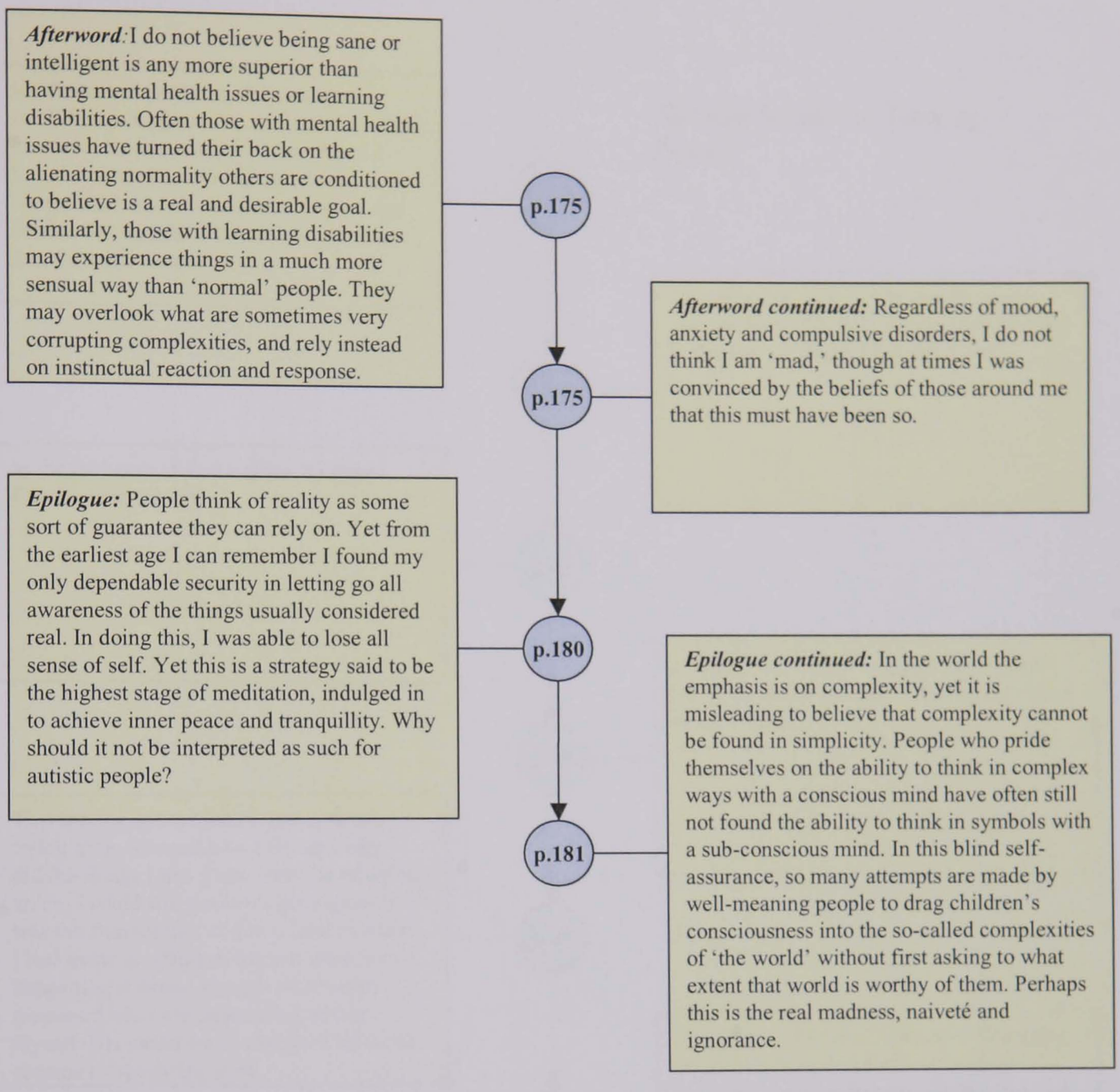
An alternative approach might employ a more inductive approach to data analysis, and one which is also more faithful to the principles of narrative inquiry. This would involve viewing both the autobiographies and forthcoming collaboratively created life-stories, in a much more holistic way. The stories themselves could provide a starting point for generating a methodological framework through the generation of themes, which could then be subjected to further analysis and interpretation.

Narrative Analysis Time-Lines

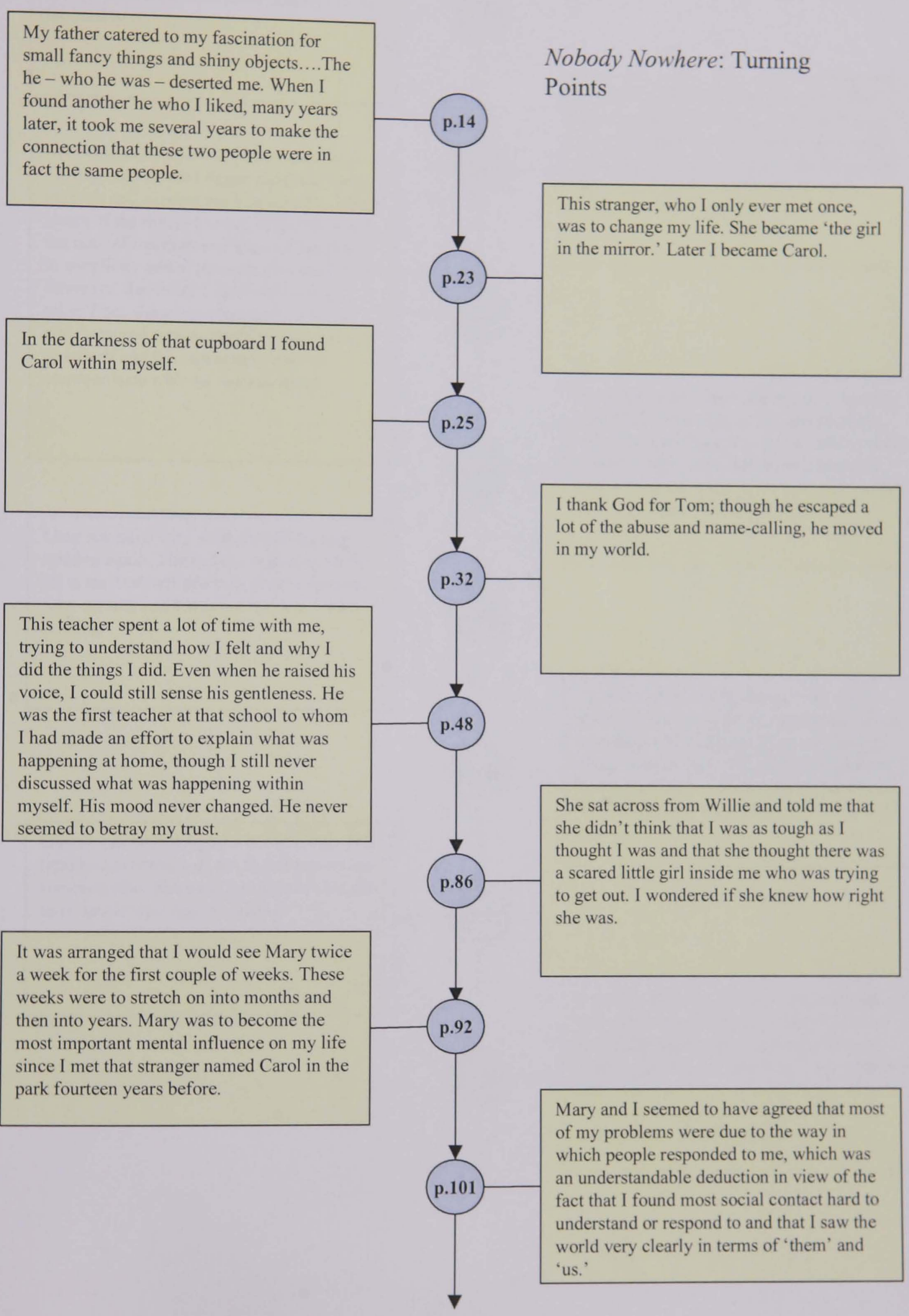
Time-Line 1

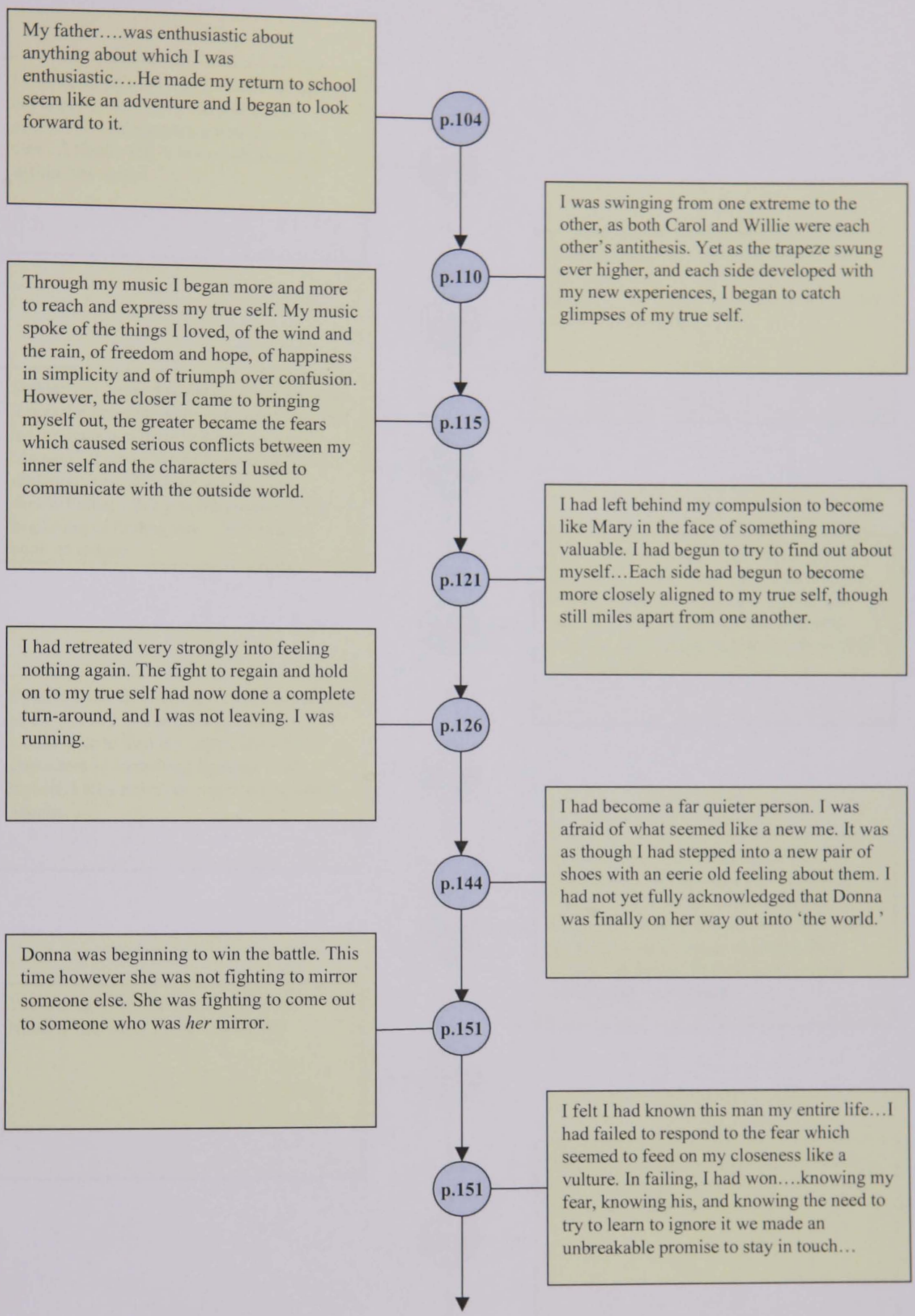


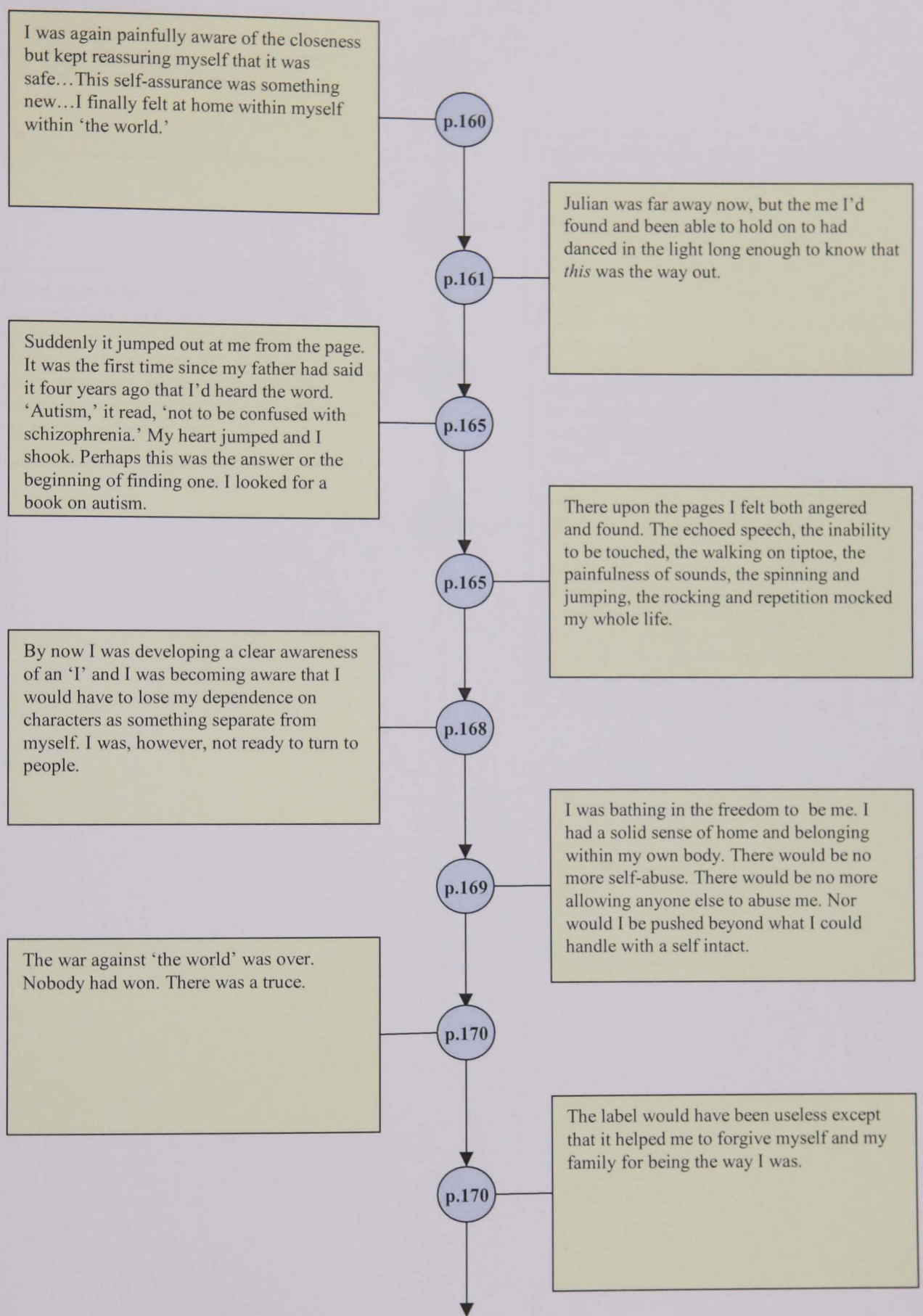

Foreword continued: Old stereotypes died as quickly as the new ones arose. Progressively, as low-functioning people showed high abilities and high-functioning people spoke about the severity of some of their challenges, the purism of high- and low-functioning fell apart.
p.10
Foreword continued: The term ASD (Autistic Spectrum Disorder) was born, allowing autism, Asperger's and PDD-NOS (Pervasive Developmental Disorder Not otherwise Specified) to be presented, for the first time, as one group. This was soon replaced with ASC (Autism Spectrum Condition) and finally with AS (being on the autistic spectrum). *Nobody Nowhere* saw the dawn on this era into a holistic view of autism as multifaceted 'normality' with the volume turned up.
p.10
"You're mad," she said with disgust. "Why didn't you just try to talk, like normal people?" she asked.
p.36
"You're mad, you know that, Donna," she once said, trying to get a reaction.
p.42
These 'helpful' people were trying to help me to 'overcome my ignorance' yet they never tried to understand the way I see the world. It seemed so simple to them. There were rules. The rules were right. I obviously needed help to learn them.
p.78
The Head of Department called me 'a complete and utter moron.'
p.114
I found that people were usually blinded by their own insecurities or egotism or selfishness. People seemed so ignorant in their self-assured black-and-white conception of 'normality.' Every so often, however, someone would wonder whether others had something to learn from me in trying to understand my differentness.
p.146
She said she had never seen him look so 'normal.' I had never felt I'd understood another individual so well. 'We think it is we who have to teach autistic people,' Kath said. 'Now I see it is us who have so much to learn from them.'
p.172

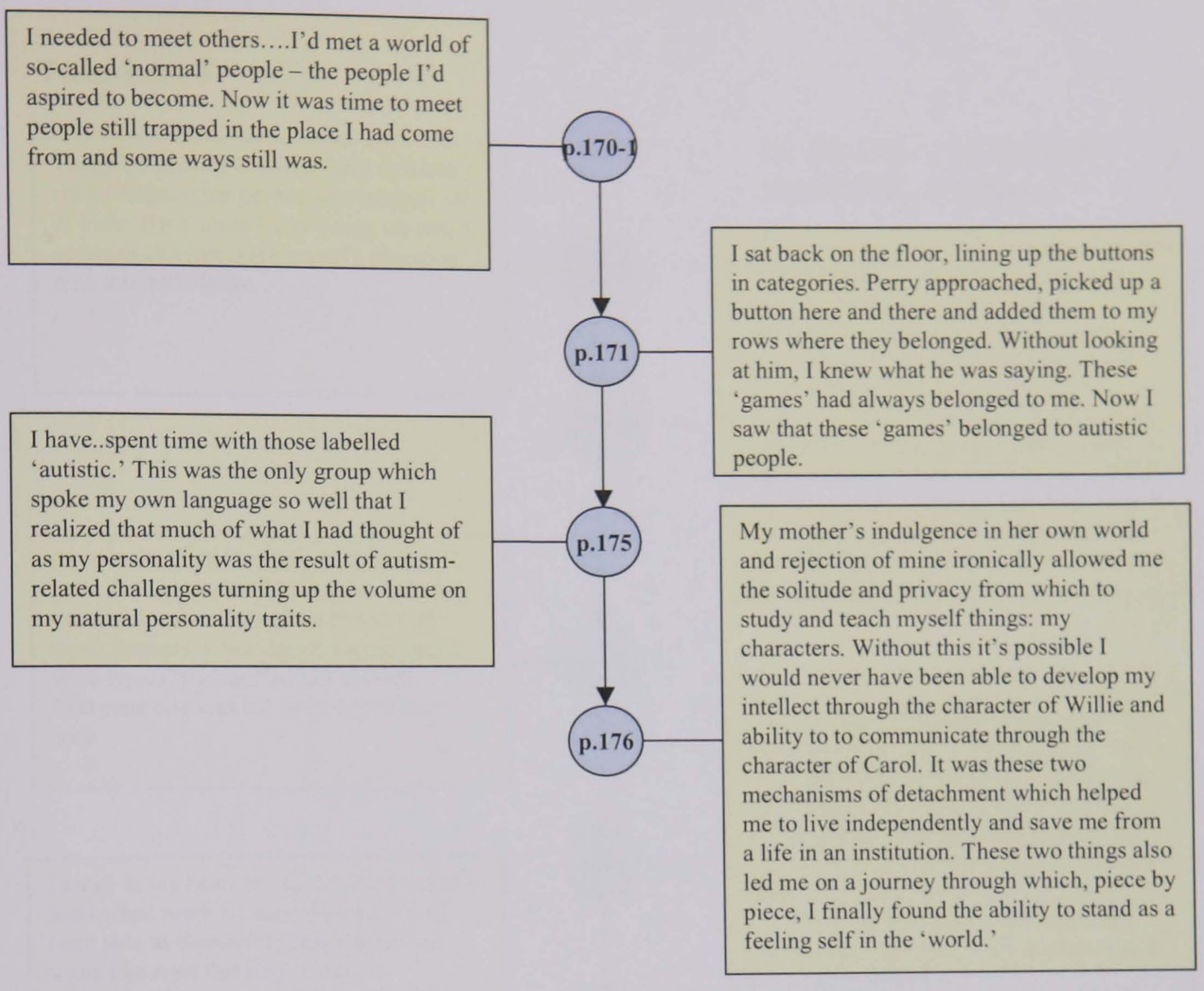

Afterword: I do not believe being sane or intelligent is any more superior than having mental health issues or learning disabilities. Often those with mental health issues have turned their back on the alienating normality others are conditioned to believe is a real and desirable goal. Similarly, those with learning disabilities may experience things in a much more sensual way than 'normal' people. They may overlook what are sometimes very corrupting complexities, and rely instead on instinctual reaction and response.
p.175
p.175
Afterword continued: Regardless of mood, anxiety and compulsive disorders, I do not think I am 'mad,' though at times I was convinced by the beliefs of those around me that this must have been so.
Epilogue: People think of reality as some sort of guarantee they can rely on. Yet from the earliest age I can remember I found my only dependable security in letting go all awareness of the things usually considered real. In doing this, I was able to lose all sense of self. Yet this is a strategy said to be the highest stage of meditation, indulged in to achieve inner peace and tranquillity. Why should it not be interpreted as such for autistic people?
p.180
p.181
Epilogue continued: In the world the emphasis is on complexity, yet it is misleading to believe that complexity cannot be found in simplicity. People who pride themselves on the ability to think in complex ways with a conscious mind have often still not found the ability to think in symbols with a sub-conscious mind. In this blind self-assurance, so many attempts are made by well-meaning people to drag children's consciousness into the so-called complexities of 'the world' without first asking to what extent that world is worthy of them. Perhaps this is the real madness, naiveté and ignorance.

Time-Line 2

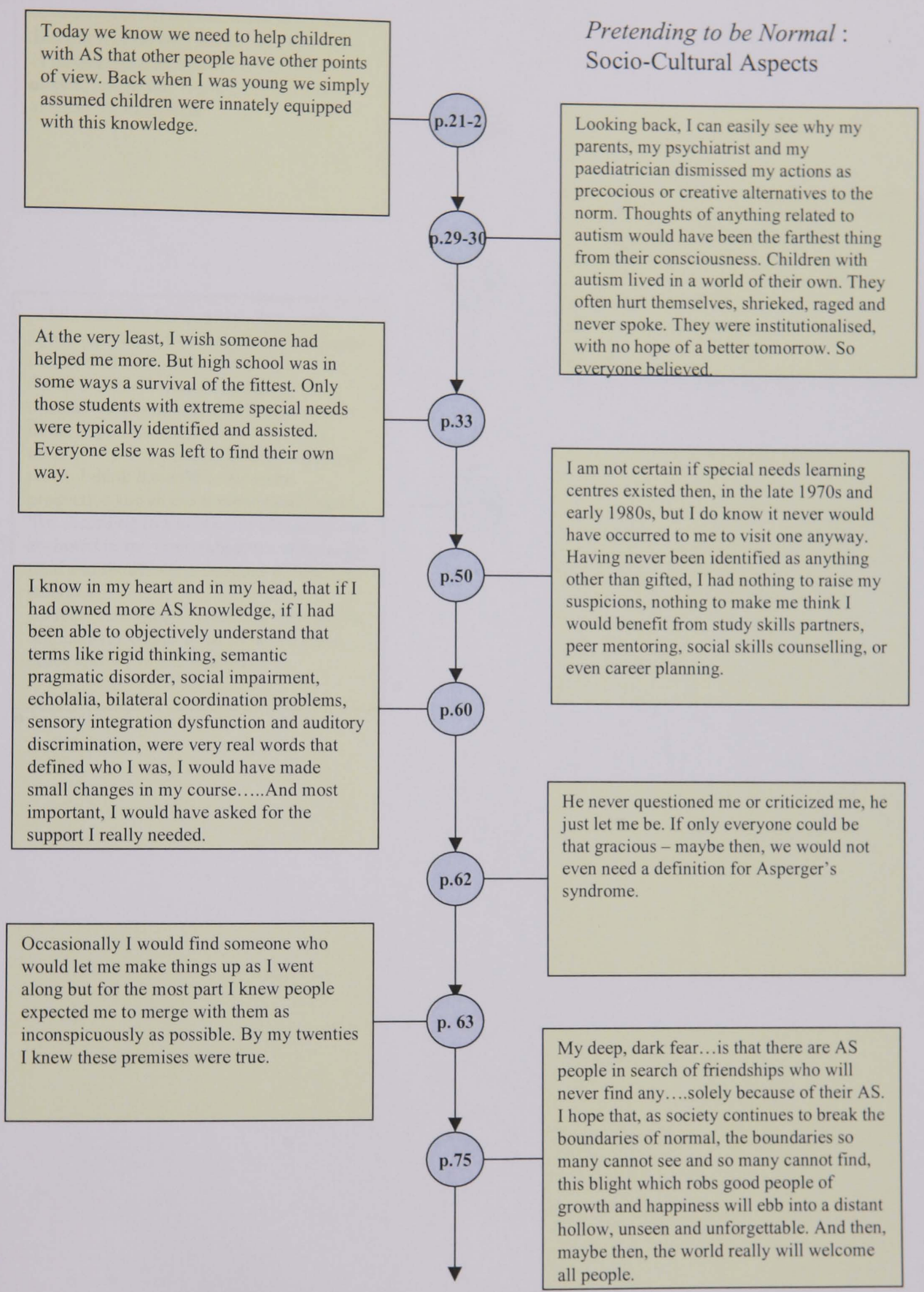

Nobody Nowhere: Turning Points
My father catered to my fascination for small fancy things and shiny objects....The he – who he was – deserted me. When I found another he who I liked, many years later, it took me several years to make the connection that these two people were in fact the same people.
p.14
This stranger, who I only ever met once, was to change my life. She became 'the girl in the mirror.' Later I became Carol.
p.23
In the darkness of that cupboard I found Carol within myself.
p.25
I thank God for Tom; though he escaped a lot of the abuse and name-calling, he moved in my world.
p.32
This teacher spent a lot of time with me, trying to understand how I felt and why I did the things I did. Even when he raised his voice, I could still sense his gentleness. He was the first teacher at that school to whom I had made an effort to explain what was happening at home, though I still never discussed what was happening within myself. His mood never changed. He never seemed to betray my trust.
p.48
She sat across from Willie and told me that she didn't think that I was as tough as I thought I was and that she thought there was a scared little girl inside me who was trying to get out. I wondered if she knew how right she was.
p.86
It was arranged that I would see Mary twice a week for the first couple of weeks. These weeks were to stretch on into months and then into years. Mary was to become the most important mental influence on my life since I met that stranger named Carol in the park fourteen years before.
p.92
Mary and I seemed to have agreed that most of my problems were due to the way in which people responded to me, which was an understandable deduction in view of the fact that I found most social contact hard to understand or respond to and that I saw the world very clearly in terms of 'them' and 'us.'
p.101

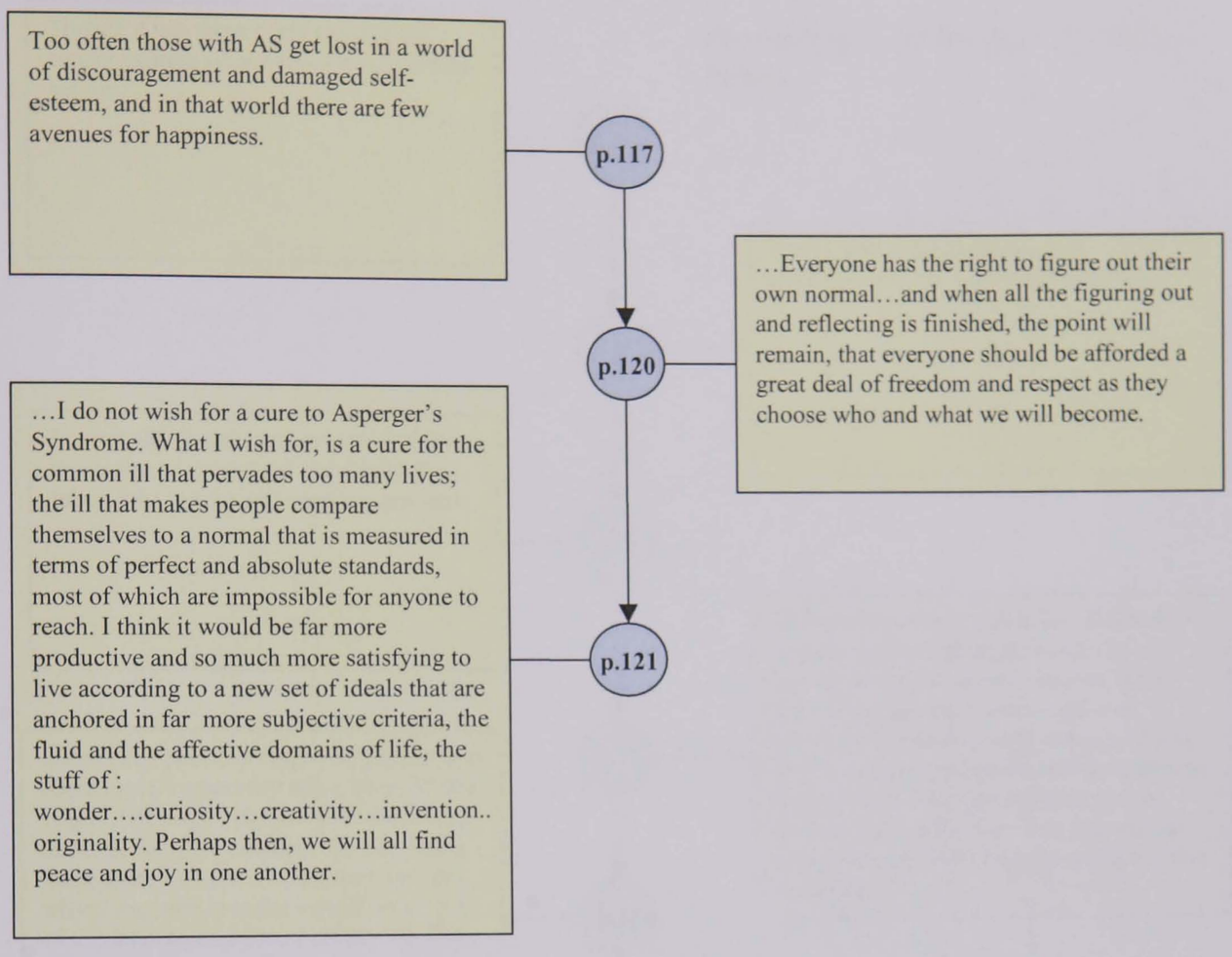

My father....was enthusiastic about anything about which I was enthusiastic....He made my return to school seem like an adventure and I began to look forward to it.
p.104
I was swinging from one extreme to the other, as both Carol and Willie were each other's antithesis. Yet as the trapeze swung ever higher, and each side developed with my new experiences, I began to catch glimpses of my true self.
p.110
Through my music I began more and more to reach and express my true self. My music spoke of the things I loved, of the wind and the rain, of freedom and hope, of happiness in simplicity and of triumph over confusion. However, the closer I came to bringing myself out, the greater became the fears which caused serious conflicts between my inner self and the characters I used to communicate with the outside world.
p.115
I had left behind my compulsion to become like Mary in the face of something more valuable. I had begun to try to find out about myself...Each side had begun to become more closely aligned to my true self, though still miles apart from one another.
p.121
I had retreated very strongly into feeling nothing again. The fight to regain and hold on to my true self had now done a complete turn-around, and I was not leaving. I was running.
p.126
I had become a far quieter person. I was afraid of what seemed like a new me. It was as though I had stepped into a new pair of shoes with an eerie old feeling about them. I had not yet fully acknowledged that Donna was finally on her way out into 'the world.'
p.144
Donna was beginning to win the battle. This time however she was not fighting to mirror someone else. She was fighting to come out to someone who was *her* mirror.
p.151
I felt I had known this man my entire life...I had failed to respond to the fear which seemed to feed on my closeness like a vulture. In failing, I had won....knowing my fear, knowing his, and knowing the need to try to learn to ignore it we made an unbreakable promise to stay in touch...
p.151


I was again painfully aware of the closeness but kept reassuring myself that it was safe…This self-assurance was something new…I finally felt at home within myself within 'the world.'
p.160
Julian was far away now, but the me I'd found and been able to hold on to had danced in the light long enough to know that *this* was the way out.
p.161
Suddenly it jumped out at me from the page. It was the first time since my father had said it four years ago that I'd heard the word. 'Autism,' it read, 'not to be confused with schizophrenia.' My heart jumped and I shook. Perhaps this was the answer or the beginning of finding one. I looked for a book on autism.
p.165
There upon the pages I felt both angered and found. The echoed speech, the inability to be touched, the walking on tiptoe, the painfulness of sounds, the spinning and jumping, the rocking and repetition mocked my whole life.
p.165
By now I was developing a clear awareness of an 'I' and I was becoming aware that I would have to lose my dependence on characters as something separate from myself. I was, however, not ready to turn to people.
p.168
I was bathing in the freedom to be me. I had a solid sense of home and belonging within my own body. There would be no more self-abuse. There would be no more allowing anyone else to abuse me. Nor would I be pushed beyond what I could handle with a self intact.
p.169
The war against 'the world' was over. Nobody had won. There was a truce.
p.170
The label would have been useless except that it helped me to forgive myself and my family for being the way I was.
p.170

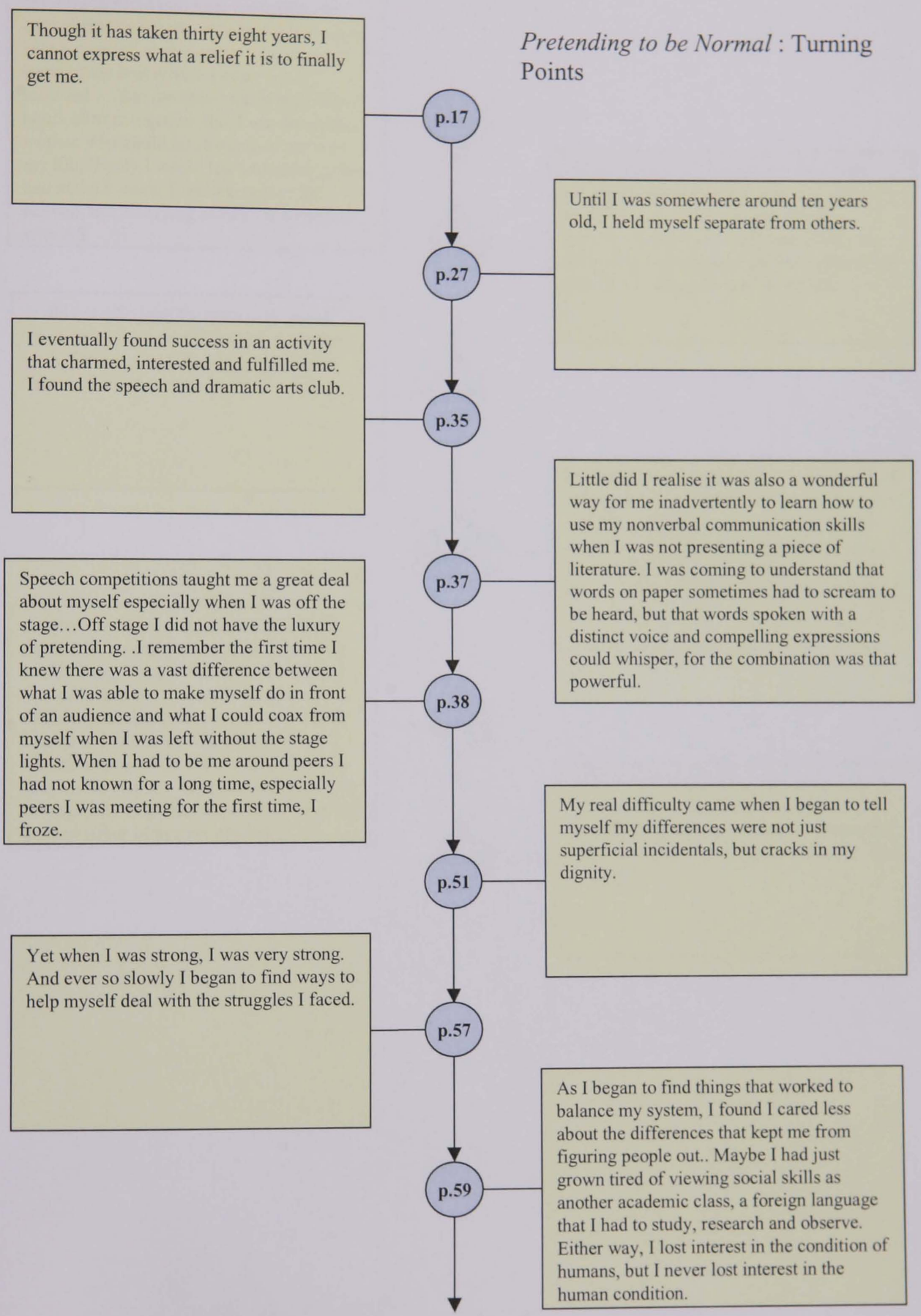

I needed to meet others….I'd met a world of so-called 'normal' people – the people I'd aspired to become. Now it was time to meet people still trapped in the place I had come from and some ways still was.
p.170-1
p.171
I sat back on the floor, lining up the buttons in categories. Perry approached, picked up a button here and there and added them to my rows where they belonged. Without looking at him, I knew what he was saying. These 'games' had always belonged to me. Now I saw that these 'games' belonged to autistic people.
I have..spent time with those labelled 'autistic.' This was the only group which spoke my own language so well that I realized that much of what I had thought of as my personality was the result of autism-related challenges turning up the volume on my natural personality traits.
p.175
My mother's indulgence in her own world and rejection of mine ironically allowed me the solitude and privacy from which to study and teach myself things: my characters. Without this it's possible I would never have been able to develop my intellect through the character of Willie and ability to to communicate through the character of Carol. It was these two mechanisms of detachment which helped me to live independently and save me from a life in an institution. These two things also led me on a journey through which, piece by piece, I finally found the ability to stand as a feeling self in the 'world.'
p.176

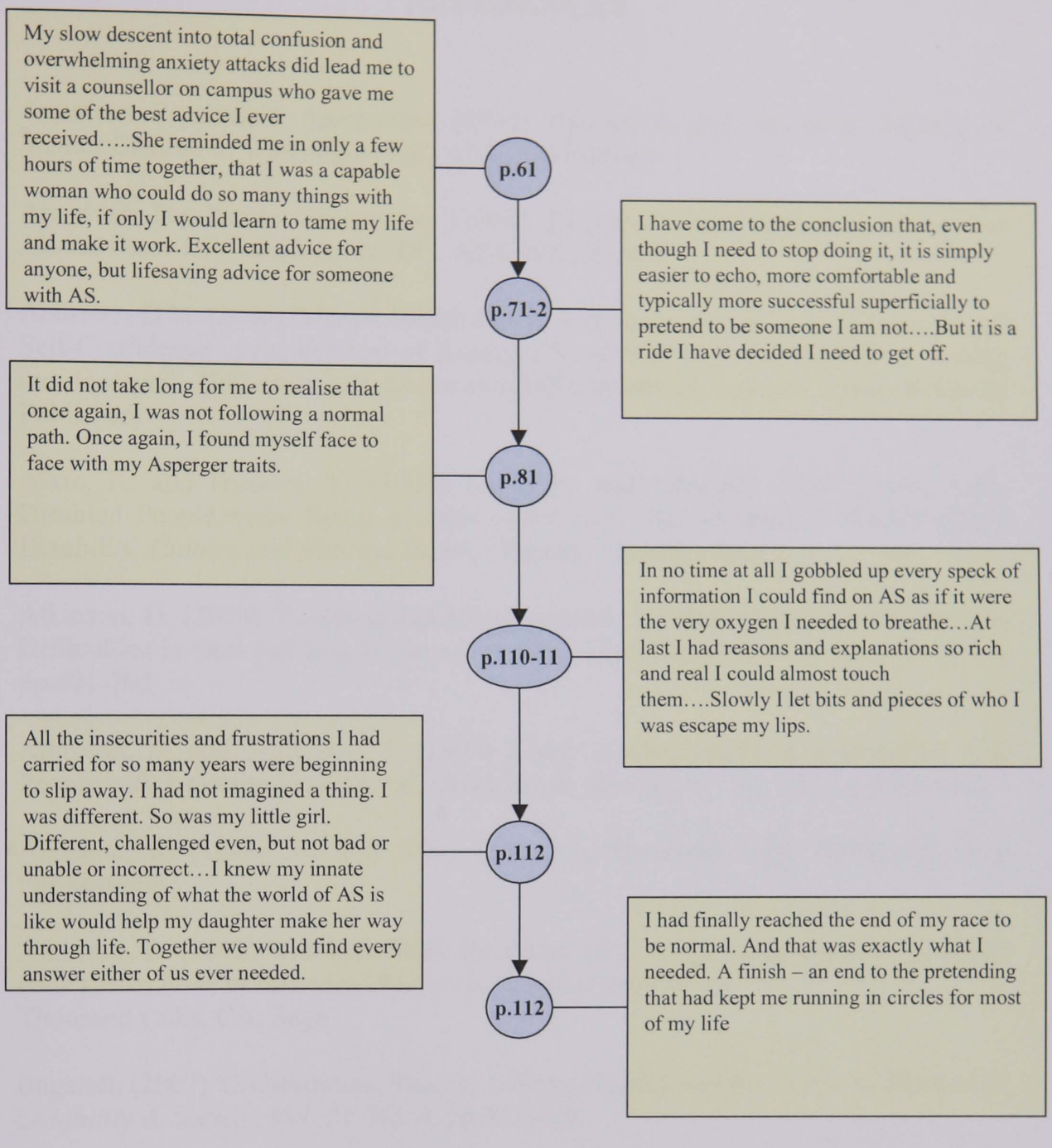
Time-Line 3


Pretending to be Normal :
Socio-Cultural Aspects
Today we know we need to help children with AS that other people have other points of view. Back when I was young we simply assumed children were innately equipped with this knowledge.
p.21-2
p.29-30
Looking back, I can easily see why my parents, my psychiatrist and my paediatrician dismissed my actions as precocious or creative alternatives to the norm. Thoughts of anything related to autism would have been the farthest thing from their consciousness. Children with autism lived in a world of their own. They often hurt themselves, shrieked, raged and never spoke. They were institutionalised, with no hope of a better tomorrow. So everyone believed.
At the very least, I wish someone had helped me more. But high school was in some ways a survival of the fittest. Only those students with extreme special needs were typically identified and assisted. Everyone else was left to find their own way.
p.33
I am not certain if special needs learning centres existed then, in the late 1970s and early 1980s, but I do know it never would have occurred to me to visit one anyway. Having never been identified as anything other than gifted, I had nothing to raise my suspicions, nothing to make me think I would benefit from study skills partners, peer mentoring, social skills counselling, or even career planning.
p.50
I know in my heart and in my head, that if I had owned more AS knowledge, if I had been able to objectively understand that terms like rigid thinking, semantic pragmatic disorder, social impairment, echolalia, bilateral coordination problems, sensory integration dysfunction and auditory discrimination, were very real words that defined who I was, I would have made small changes in my course…..And most important, I would have asked for the support I really needed.
p.60
He never questioned me or criticized me, he just let me be. If only everyone could be that gracious – maybe then, we would not even need a definition for Asperger's syndrome.
p.62
Occasionally I would find someone who would let me make things up as I went along but for the most part I knew people expected me to merge with them as inconspicuously as possible. By my twenties I knew these premises were true.
p. 63
My deep, dark fear…is that there are AS people in search of friendships who will never find any….solely because of their AS. I hope that, as society continues to break the boundaries of normal, the boundaries so many cannot see and so many cannot find, this blight which robs good people of growth and happiness will ebb into a distant hollow, unseen and unforgettable. And then, maybe then, the world really will welcome all people.
p.75


Too often those with AS get lost in a world of discouragement and damaged self-esteem, and in that world there are few avenues for happiness.
p.117
…Everyone has the right to figure out their own normal…and when all the figuring out and reflecting is finished, the point will remain, that everyone should be afforded a great deal of freedom and respect as they choose who and what we will become.
p.120
…I do not wish for a cure to Asperger's Syndrome. What I wish for, is a cure for the common ill that pervades too many lives; the ill that makes people compare themselves to a normal that is measured in terms of perfect and absolute standards, most of which are impossible for anyone to reach. I think it would be far more productive and so much more satisfying to live according to a new set of ideals that are anchored in far more subjective criteria, the fluid and the affective domains of life, the stuff of : wonder….curiosity…creativity…invention.. originality. Perhaps then, we will all find peace and joy in one another.
p.121

Time-Line 4


Pretending to be Normal : Turning Points
Though it has taken thirty eight years, I cannot express what a relief it is to finally get me.
p.17
Until I was somewhere around ten years old, I held myself separate from others.
p.27
I eventually found success in an activity that charmed, interested and fulfilled me. I found the speech and dramatic arts club.
p.35
Little did I realise it was also a wonderful way for me inadvertently to learn how to use my nonverbal communication skills when I was not presenting a piece of literature. I was coming to understand that words on paper sometimes had to scream to be heard, but that words spoken with a distinct voice and compelling expressions could whisper, for the combination was that powerful.
p.37
Speech competitions taught me a great deal about myself especially when I was off the stage…Off stage I did not have the luxury of pretending. .I remember the first time I knew there was a vast difference between what I was able to make myself do in front of an audience and what I could coax from myself when I was left without the stage lights. When I had to be me around peers I had not known for a long time, especially peers I was meeting for the first time, I froze.
p.38
My real difficulty came when I began to tell myself my differences were not just superficial incidentals, but cracks in my dignity.
p.51
Yet when I was strong, I was very strong. And ever so slowly I began to find ways to help myself deal with the struggles I faced.
p.57
As I began to find things that worked to balance my system, I found I cared less about the differences that kept me from figuring people out.. Maybe I had just grown tired of viewing social skills as another academic class, a foreign language that I had to study, research and observe. Either way, I lost interest in the condition of humans, but I never lost interest in the human condition.
p.59


My slow descent into total confusion and overwhelming anxiety attacks did lead me to visit a counsellor on campus who gave me some of the best advice I ever received…..She reminded me in only a few hours of time together, that I was a capable woman who could do so many things with my life, if only I would learn to tame my life and make it work. Excellent advice for anyone, but lifesaving advice for someone with AS.
p.61
I have come to the conclusion that, even though I need to stop doing it, it is simply easier to echo, more comfortable and typically more successful superficially to pretend to be someone I am not….But it is a ride I have decided I need to get off.
p.71-2
It did not take long for me to realise that once again, I was not following a normal path. Once again, I found myself face to face with my Asperger traits.
p.81
In no time at all I gobbled up every speck of information I could find on AS as if it were the very oxygen I needed to breathe…At last I had reasons and explanations so rich and real I could almost touch them….Slowly I let bits and pieces of who I was escape my lips.
p.110-11
All the insecurities and frustrations I had carried for so many years were beginning to slip away. I had not imagined a thing. I was different. So was my little girl. Different, challenged even, but not bad or unable or incorrect…I knew my innate understanding of what the world of AS is like would help my daughter make her way through life. Together we would find every answer either of us ever needed.
p.112
I had finally reached the end of my race to be normal. And that was exactly what I needed. A finish – an end to the pretending that had kept me running in circles for most of my life
p.112

REFERENCES

American Psychiatric Association (1980) *Diagnostic and Statistical Manual of Mental Disorders*, Washington DC: APA (3rd Edition)

American Psychiatric Association (1994) *Diagnostic and Statistical Manual of Mental Disorders*, Washington: DC: APA (4th Edition)

Andrews, D.N. (2006) 'Mental Health Issues Surrounding Diagnosis, Disclosure and Self-Confidence in the Context of Asperger Syndrome' in D. Murray (Ed.) *Coming out Asperger: Diagnosis, Disclosure and Self-Confidence*. London: Jessica Kingsley Publishers

Atkin, K. and Hussain, Y. (2003) 'Disability and Ethnicity: How Young Asian Disabled People make Sense of their Lives' in S. Riddell and N. Watson (Eds.) *Disability, Culture and Identity*, Harlow: Pearson / Prentice Hall

Atkinson, D. (2004) 'Research and Empowerment: Involving People with Learning Difficulties in Oral and Life History Research', *Disability & Society*, *Vol. 19,* No. 7, pp.691-702

Atkinson, D. and Walmsley, J. (1999) 'Using Autobiographical Approaches with People with Learning Difficulties', *Disability & Society*, *Vol. 14,* No. 2, pp.203-216

Atkinson, R. (1998) *The Life Story Interview*, Thousand Oaks, California: Sage Publications

Atkinson, R. (2002) 'The Life-Story Interview' in J. F. Gubrium and J. A. Holstein (Eds.) *Handbook of Interview Research: Context and Method*
Thousand Oaks, CA: Sage

Bagatell. (2007) 'Orchestrating Voices: Autism, Identity and the Power of Discourse', *Disability & Society*, *Vol. 22,* No. 4, pp.413-426

Bailey, A., Phillips, W. and Rutter, M. (1996) 'Autism: Towards an Integration of Clinical, Genetic, Neuropsychological and Neurobiological Perspectives', *Journal of Child Psychology and Psychiatry*, *Vol. 37,* No. 1, pp.89-117

Baird, G., Charman, T., Baron-Cohen, S., Cox, A., Swettenham, J., Wheelwright, S. and Drew, A. (2000) 'A Screening Instrument for Autism at 18 Months of age: A 6-Year Follow-up Study', *Child and Adolescent Psychiatry*, *Vol. 39,* No. 6, pp.694 -702

Baron-Cohen, S. and Bolton, P. (1993) *Autism: The Facts*, Oxford: Oxford University Press

Baron-Cohen, S., Scott, F.J., Allison, C., Williams, J., Bolton, P., Matthews, F.E. and Brayne, C. (2009) 'Prevalence of Autism-Spectrum Conditions: Uk School-based Population Study', *The British Journal of Psychiatry*, *Vol. 194,* No. 6, pp.500-509

Barron, J. and Barron, S. (1992) *There's a Boy in Here*, New York: Simon and Schuster

Bauminger, N. and Kasari, C. (2000) 'Loneliness and Friendship in High-Functioning Children with Autism', *Child Development, Vol. 71,* No. 2, pp.447-456

Beaver, R. (2003) *Educational Psychology Casework, A Practice Guide*, London: Jessica Kingsley Publishers

Bemporad, J.R. (1979) 'Adult Recollections of a Formerly Autistic Child', *Journal of Autism and Developmental Disorders, Vol. 9,* No. 2, pp.179-197

Billington, T. (2006) 'Working with Autistic Children and Young People: Sense, Experience and the Challenges for Services, Policies and Practices', *Disability & Society, Vol. 21,* No. 1, pp.1-13

Booth, T. and Booth, W. (1996) 'Sounds of Silence: Narrative Research with Inarticulate Subjects', *Disability & Society, Vol. 11,* No. 1, pp.55-70

British Psychological Society (2006) *Code of Ethics and Conduct* [online]. London BPS. Available from: http://www.bps.org.uk/document-download-area/document-download$.cfm?file_uuid=5084A882-1143-DFD0-7E6C-F1938A65C242&ext=pdf [Accessed 7 July 2009]

Brockmeier, J. (2001) 'From the End to the Beginning, Retrospective Teleology in Autobiography' in J. Brockmeier and D. Carbaugh (Eds.) *Narrative and Identity: Studies in Autobiography, Self and Culture*, Amsterdam: John Benjamins Publishing Company

Bronfenbrenner, U. (1979) *The Ecology of Human Development: Experiments by Nature and Design*, London: Harvard University Press

Bruner, J. (2001) 'Self-Making and World-Making' in J. Brockmeier and D. Carbaugh (Eds.) *Narrative and Identity: Studies in Autobiography, Self and Culture*, Amsterdam: John Benjamins Publishing Company

Bryman, A. (2004) *Social Research Methods* Oxford: Oxford University Press (2nd Edition)

Camarena, P.M. and Sarigiani, P.A. (2009) *Postsecondary Educational Aspirations of High-Functioning Adolescents With Autism Spectrum Disorders and Their Parents* [online]. Available from: http://foa.sagepub.com/cgi/rapidpdf/1088357609332675v1.pdf [Accessed 16 October 2009]

Capps, L., Losh, M. and Thurber, C. (2000) '"The Frog Ate the Bug and Made his Mouth Sad": Narrative Competence in Children with Autism', *Journal of Abnormal Child Psychology, Vol. 28,* No. 2, pp.193-204

Carlson, N.R. and Buskist (1997) *Psychology, the Science of Behaviour*, London: Allyn and Bacon (5th Edition)

Cesaroni, L. and Garber, M. (1991) 'Exploring the Experience of Autism through Firsthand Accounts', *Journal of Autism and Developmental Disorders, Vol. 21,* No. 3, pp.303-313

Chakrabarti, S. and Fombonne, E. (2005) 'Pervasive Developmental Disorders in Preschool Children: Confirmation of High Prevalence', *American Journal of Psychiatry, Vol. 162,* No. 6, pp.1133-1141

Chamak, B., Bonniau, B., Jaunay, E. and Cohen, D. (2008) 'What Can We Learn about Autism from Autistic Persons?', *Psychotherapy and Psychosomatics, Vol. 77,* No. pp.271–279

Chase, S.E. (2005) 'Narrative Inquiry, Multiple Lenses, Approaches, Voices' in N. K. Denzin and Y. S. Lincoln (Eds.) *The Sage Handbook of Qualitative Research*, London: Sage Publications (3rd Edition)

Christensen, P. and James, A. (2001) '**Introduction**. Researching Children and Childhood: Cultures of Communication' in P. Christensen and A. James (Eds.) *Research with Children, Perspectives and Practice*, London: RoutledgeFalmer

Clandinin, J. (2007, Ed.) *Handbook of Narrative Inquiry, Mapping Methodology*, Thousand Oaks, California: Sage Publications

Clandinin, J. and Connelly, M. (2000) *Narrative Inquiry: Experience and Story in Qualitative Research*, San Francisco: Jossey-Bass

Cohen, L., Manion, L. and Morrison, K. (2000) *Research Methods in Education*, Oxford: RoutledgeFalmer (5th Edition)

Connor, M. (2000) 'Asperger Syndrome (Autistic Spectrum Disorder) and the Self-Reports of Comprehensive School Students', *Educational Psychology in Practice: theory, research and practice in educational psychology, Vol. 16,* No. 3, pp.285 - 296

Corker, M. and French, S. (1998, Ed.) *Disability Discourse*, Buckingham: Open University Press

Coyle, A. (2007) 'Discourse Analysis' in E. Lyons and A. Coyle (Eds.) *Analysing Qualitative Data in Psychology*, London: Sage Publications

Creswell, J.W. (2007) *Qualitative Inquiry and Research Design, Choosing among Five Approaches*, London: Sage Publications Ltd. (2nd Edition)

Crossley, M. (2007) 'Narrative Analysis' in E. Lyons and A. E. Coyle (Eds.) *Analysing Qualitative Data in Psychology*, London: Sage Publications

Crossley, M.L. (2000) *Introducing Narrative Psychology, Self, Trauma and the Construction of Meaning*, Buckingham: Open University Press

Cunningham, D. (1992) 'Beyond Educational Psychology: Steps Toward an Educational Semiotic', *Educational Psychology Review, Vol. 4,* No. 2, pp.165-194

Curtin, M. and Clarke, G. (2005) 'Listening to Young People with Physical Disabilities' Experiences of Education', *International Journal of Disability, Development and Education, Vol. 52,* No. 3, pp.195-214

Daiute, C. and Lightfoot, C. (2004, Eds.) *Narrative Analysis, Studying the Development of Individuals in Society*, Thousand Oaks: Sage Publications

Davidson, J. (2007) 'In a World of her Own...Re-presenting Alienation and Emotion in the Lives and Writings of Women with Autism', *Gender, Place and Culture, Vol. 14,* No. 6, pp.659-677

De Shazer, S. (1985) *Keys to Solutions in Brief Therapy*, London: Norton & Company

Denzin, N. (1989) *Interpretive Biography*, London: Sage Publications

Department for Education and Skills (2001) *Special Educational Needs and Disability Act 2001,* London: DfES

DeSocio, J.E. (2005) 'Accessing Self-development through Narrative Approaches in Child and Adolescent Psychotherapy', *Journal of Child and Adolescent Psychiatric Nursing, Vol. 18,* No. 2, pp.53-61

Disability Rights Commission (2006) *Schools and the Disability Equality Duty in England and Wales [online],* DRC. Available from http://83.137.212.42/sitearchive/DRC/library/publications/disability_equality_duty/schools_and_the_ded_engl_wales.html [Accessed 6 April 2009]

Ehlers, S. and Gillberg, C. (1993) 'The Epidemiology of Asperger Syndrome. A Total Population Study', *Journal of Child Psychology and Psychiatry, Vol. 34,* No. 8, pp.1327-1350

Etherington, K. (2004) *Becoming a Reflexive Researcher*, London: Jessica Kingsley Publishers

Evans, S. (2005) 'The Development of a Group Consultation Approach to Service Delivery', *Educational Psychology in Practice: theory, research and practice in educational psychology, Vol. 21,* No. 2, pp.131 - 146

Frederickson, N. and Cline, T. (2002) *Special Educational Needs, Inclusion and Diversity*, Buckingham: Open University Press

Freeman, M. (2001) **'From Substance to Story,** Narrative, Identity, and the Reconstruction of the Self' in J. Brockmeier and D. Carbaugh (Eds.) *Narrative and Identity: Studies in Self, Autobiography and Culture*, Amsterdam: John Benjamins Publishing Company

Freeman, M. (2004) 'Data are Everywhere, Narrative Criticism in the Literature of Experience' in C. Daiute and C. Lightfoot (Eds.) *Narrative Analysis, Studying the Development of Individuals in Society*, Thousand Oaks: Sage Publications

Freeman, M. and Brockmeier, J. (2001) 'Narrative Integrity: Autobiographical Identity and the Meaning of the "Good Life" ' in J. Brockmeier and D. Carbaugh (Eds.) *Narrative and Identity: Studies in Autobiography, Self and Culture*, Amsterdam: John Benjamins Publishing Company

Frith, U. (1989) *Autism - Explaining the Enigma*, London: Basil Blackwell Ltd

Gergen, K. (2001) 'Self-Narration in Social LIfe' in M. Wetherell, S. Taylor and S. J. Yates (Eds.) *Discourse: Theory and Practice*, London: Sage Publications

Gillberg, C. (1991) 'Clinical and Neurobiological Aspects of Asperger Syndrome' in U. Frith (Ed.) *Autism and Asperger Syndrome*, Cambridge: Cambridge University Press

Gillberg, C. (1992) 'The Emanuel Miller Memorial Lecture 1991', *Journal of Child Psychology and Psychiatry, Vol. 33,* No. 5, pp.813-842

Gillberg, C. (1998) 'Asperger Syndrome and High-Functioning Autism', *The British Journal of Psychiatry, Vol. 172,* No. 3, pp.200-209

Gillberg, C. and Gillberg, I.C. (1989) 'Asperger Syndrome - Some Epidemiological Considerations: A Research Note', *Journal of Child Psychology and Psychiatry, Vol. 30,* No. 44, pp.631-638

Gillman, M. (2004) 'Diagnosis and Assessment in the Lives of Disabled People: Creating Potentials / Limiting Possibilities?' in J. Swain, S. French, C. Barnes and C. Thomas (Eds.) *Disabling Barriers - Enabling Environments*, London: Sage Publications

Gillman, M., Heyman, B. and Swain, J. (2000) 'What's in a Name? The Implications of Diagnosis for People with Learning Difficulties and their Family Carers', *Disability & Society, Vol. 15,* No. 3, pp.389 - 409

Gillman, M., Swain, J. and Heyman, B. (1997) 'Life History or "Case" History: the Objectification of People with Learning Difficulties Through the Tyranny of Professional Discourses', *Disability and Society, Vol. 12,* No. 5, pp.675-693

Goldman, S. (2008) 'Brief Report: Narratives of Personal Events in Children with Autism and Developmental Language Disorders: Unshared Memories', *Journal of Autism and Developmental Disorders, Vol. 38,* No. 10, pp.1982-1988

Goodley, D. (1996) 'Tales of Hidden Lives: a Critical Examination of Life History Research with People who have Learning Difficulties', *Disability & Society, Vol. 11,* No. 3, pp.333-348

Goodley, D. (2001) '*Learning Difficulties*, the Social Model of Disability and Impairment: Challenging Epistemologies', *Disability & Society, Vol. 16,* No. 2, pp.207-231

Goodley, D., Lawthon, R., Clough, P. and Moore, M. (2004) *Researching Life Stories, Method, Theory and Analyses in a Biographical Age*, London: RoutledgeFalmer

Grandin, T. (2006) *Thinking in Pictures and other Reports from Life with Autism*, London: Bloomsbury Publishing, Plc.

Grandin, T. and Scariano, M. (1986) *Emergence: Labelled Autistic*, Novato, California: Arena

Gray, D.E. (2001) 'Accommodation, Resistance and Transcendence: Three Narratives of Autism', *Social Science & Medicine, Vol. 53,* No. 9, pp.1247-1257

Green, J., Gilchrist, A., Burton, D. and Cox, A. (2000) 'Social and Psychiatric Functioning in Adolescents with Asperger Syndrome Compared with Conduct Disorder', *Journal of Autism and Developmental Disorders, Vol. 30,* No. 4, pp.279-293

Greenway, C. (2000) 'Autism and Asperger Syndrome: Strategies to Promote Prosocial Behaviours', *Educational Psychology in Practice: theory, research and practice in educational psychology, Vol. 16,* No. 4, pp.469 - 486

Grey, I.M., Bruton, C., Honan, R., McGuinness, R. and Daly, M. (2007) 'Co-operative Learning for Children with an Autistic Spectrum Disorder (ASD) in Mainstream and Special Class Settings: An Exploratory Study', *Educational Psychology in Practice: theory, research and practice in educational psychology, Vol. 23,* No. 4, pp.317-327

Gus, L. (2000) 'Autism: Promoting Peer Understanding', *Educational Psychology in Practice: theory, research and practice in educational psychology, Vol. 16,* No. 4, pp.461-468

Gutstein, S.E. (2003) 'Can my Baby Learn to Dance? Exploring the Friendships of Asperger Teens' in L. Holliday Willey (Ed.) *Asperger Syndrome in Adolescence, Living with the Ups and Downs and Things in Between*, London: Jessica Kingsley Publishers

Happé, F. (1991) 'The Autobiographical Writings of Three Asperger Syndrome Adult: Problems of Interpretation and Implications for Theory' in U. Frith (Ed.) *Autism and Asperger Syndrome*, Cambridge: Cambridge University Press

Harre, R. (2001) 'Metaphysics and Narrative: Singularities and Multiplicities of Self' in J. Brockmeier and D. Carbaugh (Eds.) *Narrative and Identity: Studies in Self, Autobiography and Culture*, Amsterdam: John Benjamins Publishing Company

Hilton, C., Graver, K. and LaVesser, P. (2006) 'Relationship between Social Competence and Sensory Processing in Children with High Functioning Autism Spectrum Disorders', *Research in Autism Spectrum Disorders*, *Vol. 1,* No. 2, pp.164-173

Hobson, R.P. (1993a) *Autism and the Development of the Mind*, Hove / Hillsdale: Laurence Erlbaum Association

Holliday Willey, L. (1999) *Pretending to be Normal, Living with Asperger's Syndrome*, London: Jessica Kingsley Publishers

Hughes, B. and Paterson, K. (1997) 'The Social Model of Disability and the Disappearing Body: towards a Sociology of Impairment', *Disability & Society*, *Vol. 12,* No. pp.325-340

Humphrey, N. and Lewis, S. (2008) ' "Make me Normal": The Views and Experiences of Pupils on the Autistic Spectrum in Mainstream Secondary Schools', *Autism*, *Vol. 12,* No. 1, pp.23-46

Ibanez-Clark, M. (2007) 'Inner-City Children in Sharper Focus: Sociology of Childhood and Photo Elicitation Interviews' in G. C. Stanczak (Ed.) *Visual Research Methods: Image, Society and Representation*, London: Sage Publications

Jackson, L. (2002) *Freaks, Geeks & Asperger Syndrome. A User Guide to Adolescence*, London: Jessica Kingsley Publishers Ltd.

Jones, R., S.P., Quigney, C. and Huws, J.C. (2003) 'First-hand Accounts of Sensory Perceptual Experiences in Autism: a Qualitative Analysis', *Journal of Intellectual & Developmental Disability,*, *Vol. 28,* No. 2, pp.112-121

Jones, R.S.P., Zahl, A. and Huws, J.C. (2001) 'First-hand Accounts of Emotional Experiences in Autism: a Qualitative Analysis', *Disability & Society*, *Vol. 16,* No. 3, pp.393-401

Jordan, R. and Powell, S. (1995) *Understanding and Teaching Children with Autism*, London: Wiley

Kabot, S., Masi, W. and Segal, M. (2003) 'Advances in the Diagnosis and Treatment of Autism Spectrum Disorders', *Professional Psychology, Research and Practice*, *Vol. 34,* No. 1, pp.26-33

Kanner, L. (1943) 'Autistic Disturbances of Affective Contact', *Nervous Child*, *Vol. 2,* No. pp.217-250

Keil, S., Miller, O. and Cobb, R. (2006) 'Special Educational Needs and Disability', *British Journal of Special Education, Vol. 33,* No. 4, pp.168-172

Kelly, G.A. (1955) *The Psychology of Personal Constructs*, New York: Norton

Kelly, G.A. (1963) *A Theory of Personality: The Psychology of Personal Constructs*, New York: W.W. Norton

Korn, C. (1997) 'Applying a Narrative Frame to the Assessment of Children', *Canadian Journal of School Psychology, Vol. 13,* No. 1, pp.28-37

Lasser, J. and Corley, K. (2008) 'Constructing Normalcy: A Qualitative Study of Parenting Children with Asperger's Disorder', *Educational Psychology in Practice, Vol. 24,* No. 4, pp.335-346

Lauritsen, M., Mors, O., Mortensen, P.B. and Ewald, H. (1999) 'Infantile Autism and Associated Autosmal Chromosome Abnormalities: A Register-based Study and a Literature Survey', *Journal of Child Psychology and Psychiatry, Vol. 40,* No. 3, pp.335-345

Lawson, W. (1998) *Life Behind Glass, A Personal Account of Autism Spectrum Disorder*, London: Jessica Kingsley Publishers

Lieblich, A., Tuval-Mashiach, R. and Zilber, T. (1998) *Narrative Research, Reading Analysis and Interpretation*, London: Sage Publications

Lobianco, A.F. and Sheppard-Jones, K. (2007) 'Perceptions of Disability as Related to Medical and Social Factors', *Journal of Applied Social Psychology, Vol. 37,* No. 1, pp.1-13

Losh, M. and Capps, L. (2003) 'Narrative Ability in High-Functioning Children with Autism or Asperger's Syndrome', *Journal of Autism and Developmental Disorders, Vol. 33,* No. 3, pp.239-251

Losh, M. and Capps, L. (2006) 'Understanding of Emotional Experience in Autism: Insights From the Personal Accounts of High-Functioning Children With Autism', *Developmental Psychology, Vol. 42,* No. 5, pp.809-818

Lovaas, O. (1977) *The Autistic Child and Child Development through Behaviour Modification*, New York Wiley

MacKay, T. (2006) 'The Educational Psychologist as Community Psychologist: Holistic Child Psychology across Home, School and Community', *Educational and Child Psychology, Vol. 23,* No. 1, pp.7-67

Manthei, R. (1997) *Counselling, The Skills of Finding Solutions to Problems*, London: Routledge

Marchant, R., Jones, M., Julyan, A. and Giles, A. (1999) *Listening on all Channels: Consulting with Disabled Children and Young People*, Brighton: Triangle

Maslow, A.H. (1970) *Motivation and Personality*, New York: Harper & Row

Mason, J. (2002) *Qualitative Researching* London: Sage Publications (2nd Edition)

McLeod, J. (2006) 'Narrative Thinking and the Emergence of Postpsychological Therapies', *Narrative Inquiry, Vol. 16,* No. pp.201-210

Molloy, H. and Vasil, L. (2002) 'The Social Construction of Asperger Syndrome: the Pathologising of Difference?', *Disability & Society, Vol. 17,* No. 6, pp.659-669

Molloy, H. and Vasil, L. (2004) *Asperger Syndrome, Adolescence and Identity*, London: Jessica Kingsley Publishers

Moore, J. (2005) 'Recognising and Questioning the Epistemological Basis of Educational Psychology Practice', *Educational Psychology in Practice: theory, research and practice in educational psychology, Vol. 21,* No. 2, pp.103 - 116

Mundy, P., Sigman, M. and Kasari, C. (1990) 'A Longitudinal Study of Joint Attention and Language Development in Autistic Children', *Journal of Autism and Developmental Disorders, Vol. 20,* No. 1, pp.115-128

Newton, C. and Wilson, D. (1999) *Circles of Friends*, Dunstable: Folens Limited

O'Neill, J.L. (1999) *Through the Eyes of Aliens, a Book about Autistic People*, London: Jessica Kingsley Publishers

O'Neill, M. and Jones, R.S.P. (1997) 'Sensory-Perceptual Abnormalities in Autism: A Case For More Research?', *Journal of Autism and Developmental Disorders, Vol. 27,* No. 3, pp.283-293

Oliver, M. (1990) *The Politics of Disablement*, London: Macmillan

Payne, S. (2007) 'Grounded Theory' in E. Lyons and A. Coyle (Eds.) *Analysing Qualitative Data in Psychology*, London: Sage Publications

Pellegrini, D.W. (2009) 'Applied Systemic Theory and Educational Psychology: Can the Twain ever Meet?', *Educational Psychology in Practice: theory, research and practice in educational psychology, Vol. 25,* No. 3, pp.271 - 286

Pinnegar, S. and Daynes, J.G. (2007) 'Locating Narrative Inquiry Historically' in J. Clandinin (Eds.) *Handbook of Narrative Inquiry, Mapping a Methodology*, Thousand Oaks, California: Sage Publications

Preece, D. (2002) 'Consultation with Children with Autistic Spectrum Disorders about their Experience of Short-term Residential Care', *British Journal of Learning Disabilities, Vol. 30,* No. 3, pp.97-104

Provis, M. (1992) *Dealing with Difficulty: A Systems Approach to Problem Behaviour*, London: Hodder & Stoughton

Ravenette, T. (1999) *Personal Construct Theory in Educational Psychology, A Practitioner's View*, London: Whurr Publishers Ltd

Reilly, C., Campbell, A. and Keran, P. (2009) 'Screening for Asperger Syndrome in School-Age Children: Issues and Instruments', *Educational Psychology in Practice, Vol. 25,* No. 1, pp.37-52

Reissman, C.K. (1993) *Narrative Analysis*, London: Sage Publications

Rhodes, J. (1993) 'The Use of Solution-Focused Brief Therapy in Schools', *Educational Psychology in Practice, Vol. 9,* No. 1, pp.27-34

Roberts, B. (2002) *Biographical Research*, Buckingham: Open University Press

Robson, C. (2002) *Real World Research*, Oxford: Blackwell Publishing (2nd Edition)

Rogers, C. (1951) *Client-Centered Therapy*, Boston: Houghton Mifflin

Rose, I. (2008) 'Autistic Autobiography or Autistic Life Narrative?', *Journal of Literary Disability, Vol. 2,* No. 1, pp.44-54

Rose, R. and Philpot, T. (2005) *The Child's Own Story, Life Story Work with Truamatized Children*, London: Jessica Kingsley Publishers

Rutter, M. (2005) 'Autism Research: Lessons from the Past and Prospects for the Future', *Journal of Autism and Developmental Disorders, Vol. 35,* No. 2, pp.241-257

Rutter, M., Caspi, A. and Moffitt, T. (2003) 'Using Sex Differences in Psychopathology to Study Causal Mechanisms: Unifying Issues and Research Strategies', *Journal of Child Psychology and Psychiatry, Vol. 44,* No. 8, pp.1092-1115

Ryan, T. and Walker, R. (1985) *Making Life Story Books*, London: British Agencies for Adoption and Fostering

Ryan, T. and Walker, R. (1993) *Life-Story Work*, London: British Agencies for Adopting and Fostering (2nd Edition)

Seligman, E.P. and Csikszentmihalyi, M. (2000) 'Positive Psychology, An Introduction', *American Psychologist, Vol. 55,* No. 1, pp.5-14

Smith, S. (1996) 'Taking it to a Limit One More Time' in S. Smith and J. Watson (Eds.) *Getting a Life: Everyday Uses of Autobiography*, Minneapolis: University of Minnesota

Smukler, D. (2005) 'Unauthorized minds: How "Theory of Mind" Theory Misrepresents Autism', *Mental Retardation, Vol. 43,* No. 1, pp.11-24

Steffenburg, S. and Gillberg, C. (1986) 'Autism and Autistic-like Conditions in Swedish Rural and Urban Areas: a Population Study', *British Journal of Psychiatry, Vol. 149,* No. 1, pp.81-87

Stevens, C. and Stevens, N. (2008) *A Real Boy, How Autism Shattered our Lives - and Made a Family from the Pieces*, London: Michael O'Mara Books Limited

Strauss, A. and Corbin, J. (1990) *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*, Newbury Park, CA: Sage

Stringer, P., Powell, J. and Burton, S. (2006) 'Developing a Community Psychology Orientation in an Educational Psychology Service', *Educational and Child Psychology, Vol. 23,* No. 1, pp.59-67

Swain, J., French, S. and Cameron, C. (2003) *Controversial Issues in a Disabling Society*, Buckingham: Open University Press

Tager-Flusberg, H. (2000) 'Language and Understanding Minds: Connections in Autism' in S. Baron-Cohen, H. Tager-Flusberg and D. J. Cohen (Eds.) *Understanding Other Minds: Perspectives from Developmental Cognitive Neuroscience*, Oxford: Oxford University Press (2nd Edition)

Tammet, D. (2006) *Born on a Blue Day*, London: Hodder & Stoughton

Thomas, C. (2007) *Sociologies of Disability and Illness*, Basingstoke: Palgrave Macmillan

Thomson, P. (2008) 'Children and Young People, Voices in Visual Research' in P. Thomson (Ed.) *Doing Visual Research with Children and Young People*, London: Routledge

Tobias, A. (2009) 'Supporting Students with Autistic Spectrum Disorder (ASD) at Secondary School: A Parent and Student Perspective', *Educational Psychology in Practice: theory, research and practice in educational psychology, Vol. 25,* No. 2, pp.151 - 165

Traustadottir, R. and Johnson, K. (2000, Eds.) *Women with Intellectual Disabilities, Finding a Place in the World*, London: Jessica Kingsley Publishers

Trevarthen, A. (1996) *Children with Autism*, London: Jessica Kingsley

Tutt, R., Powell, S. and Thornton, M. (2006) 'Educational Approaches in Autism: What we Know about What we do', *Educational Psychology in Practice: theory, research and practice in educational psychology, Vol. 22,* No. 1, pp.69-81

Volkmar, F.R. and Cohen, D.J. (1985) 'The Experience of Infantile Autism: A First-Person Account by Tony W', *Journal of Autism and Developmental Disorders, Vol. 15,* No. 1, pp.47-54

Volkmar, F.R. and Klin, A. (2005) 'Issues in the Classification of Autism and Related Conditions' in F. R. Volkmar, A. Paul and D. Cohen (Eds.) *Handbook of Autism and Pervasive Developmental Disorder*, Hoboken, NJ: John Wiley and Sons (3rd Edition)

Wagner, P. and Gillies, E. (2001) 'Consultation: A Solution-Focussed Approach' in Y. Ajmal and I. Rees (Eds.) *Solutions in Schools, Creative Applications of Solution Focussed Brief Thinking with Young People and Adults*, London: BT Press

Waltz, M. (2005) 'Reading Case Studies of People with Autistic Spectrum Disorders: a Cultural Studies Approach to Issues of Disability Representation', *Disability & Society*, *Vol. 20,* No. 4, pp.421 - 435

Whitaker, P. (2006) 'Why's it all so Difficult? Sharing the Diagnosis with the Young Person' in D. Murray (Ed.) *Coming out Asperger: Diagnosis, Disclosure and Self-Confidence*, London: Jessica Kingsley Publishers

Whitaker, P., Barratt, P., Joy, H., Potter, M. and Thomas, G. (1998) 'Children with Autism and Peer Group Support: using "Circles of Friends" ', *British Journal of Special Education*, *Vol. 25,* No. 2, pp.60-64

White, S. and Roberson-Nay, R. (2009) 'Anxiety, Social Deficits, and Loneliness in Youth with Autism Spectrum Disorders', *Journal of Autism and Developmental Disorders*, *Vol. 39,* No. 7, pp.1006-1013

Wilkinson, L.A. (2005) 'Supporting the Inclusion of a Student with Asperger Syndrome: A Case Study using Conjoint Behavioural Consultation and Self-management', *Educational Psychology in Practice: theory, research and practice in educational psychology*, *Vol. 21,* No. 4, pp.307 - 326

Williams, D. (1992) *Nobody Nowhere, the Remarkable Autobiography of an Autistic Girl*, London: Jessica Kingsley Publishers (2nd Edition)

Wing, L. (1981) 'Sex Ratios in Early Childhood Autism and Related Conditions', *Psychiatry Research*, *Vol. 5,* No. 2, pp.129-137

World Health Organization (1993) *Mental Disorders: A Glossary and Guide to Their Classification in Accordance with the 10th Revision of the International Classification of Diseases: Research Diagnostic Criteria (ICD-10)*, Geneva: WHO

Zarb, G. (1992) 'On the Road to Damascus: First Steps towards changing the Relations of Disability Research Production', *Disability, Handicap and Society*, *Vol. 7,* No. pp.125-138